

CHAPTER 2

LIVING THE DRAMA

2.1 RESEARCH QUESTIONS

According to Reid (1992:657) one of the most striking features of the response to the HIV epidemic is the few policies and programmes developed that relate to women's life situations. Although the daily lives of women and the complex network of relationships and structures which shape them are well known to women and well documented, the theories, research agendas, policies and programmes surrounding the pandemic have not been grounded in or informed by these experiences.

Perhaps this could be attributed to "third person accounts" and "generic sociology" that have not, in fact, told us anything about women's experiences (Judy Long in Reinharz 1992:133). First person accounts are required to understand the subjectivity of a social group that is "muted", excised from history, "invisible" in the official records of their culture. Some feminist scholars, including myself, believe that injustices can be righted (to some extent) when "people tell their stories".

Stories told by women do not occur as monologues, but are the product of developing relationships as clearly demonstrated in the drama: "Basadi ba Tswara." Julia Swindells (in Reinharz 1992:138) asks the question: "Who is speaking when women speak for themselves?" She believes we have been naïve in not analysing the conditions under which voices are speaking. Her scepticism about the "authenticity" of voices hinges on the fact that their very production may be a form of oppression. Even when women speak for themselves, they can perpetuate systems of injustice through the discourses they use to interpret their stories.

I am the general manager of an NGO, Heartbeat, which aims to alleviate the suffering of orphaned and vulnerable children by facilitating change in communities. I am also an ordained minister of religion at the DRC Skuilkrans, in Pretoria, commissioned with the task 'HIV/AIDS'. In addition, I am a female from a privileged middle-class background.

My interest in the stories of women infected and/or affected by HIV/AIDS was triggered by the fact that women are the caregivers of ninety-eight percent of the children in Heartbeat's programmes. These women are mostly unemployed and have lost fathers, husbands, daughters and sons to HIV/AIDS. Some of them are infected themselves.

It is these women who are expected to carry the extra burden of care for the infected and the affected, lacking care and access to care themselves. Furthermore their voices have been silenced by discourses of patriarchy, gender, culture and the history of apartheid, which means that they seldom know how to speak out for themselves. Government policies on HIV/AIDS imply that it is and should be expected from African women to take care of the sick and the orphaned in their communities, because traditionally, African women have always done so. This discourse in African society is also muting the voices of the women.

Against this background, I realised that it must be possible to facilitate ways of letting women in historically challenged communities, infected and affected by HIV/AIDS, tell their untold stories about care and/or the lack of care. Therefore I set a research question to find a way that would help me to empower women without marginalizing them. I am aware that I initiated these questions without consulting the women. Therefore, I endeavoured to deconstruct the power discourse and ensure power-sharing between myself (as researcher/white/educated/middleclass) and those women whose stories I included.

The research questions are:

Firstly, what do the untold stories of South African women in historically disadvantaged communities, infected and/or affected by HIV/AIDS, tell us about care and the lack of care?

Secondly, how can women infected/affected by HIV/AIDS inform 'power structures' regarding their experiences of care/lack of care?

2.2 RESEARCH AIMS AND OBJECTIVES

In order to assist my research into these questions, I formulated the research aims and objectives set out below. While doing this, I was very aware that the women who would be involved did not have a say in the questions and research aims as I formulated them. Thus the research was not a fully participatory research project where power, questions, aims and ways to reach aims would be shared, as described in Bishop (1996). The absence of their full participation necessitated the need to deconstruct the power structures, which could potentially create distance between the co-researchers and myself.

The main aim of this research was to reach a holistic understanding of the untold stories of women in historically challenged communities, infected and affected by HIV/AIDS, and specifically about their experiences of care and the lack of care. The two secondary aims were: 1) to research alternative ways and means of making the unheard stories known in South African society; and 2) to disseminate research findings on the stories of these women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

In order to achieve these aims, I drafted more specific objectives. The first objective was to deconstruct discourses embedded in patriarchy, gender, and culture in order to empower women infected/affected by HIV/AIDS to tell their stories about care and/ or the lack of care. I endeavoured to use post-modern

narrative social construction discourse (Freedman & Combs 1996:22) and post-modern theologies.

Adopting a post-modern narrative social constructionist worldview offers useful ideas about how power, knowledge and 'truth' are negotiated in families and larger cultural aggregations (Freedman & Combs 1996:22). The purpose of using post-modern theology, which questions dominant discourses in our society, is to challenge the ethical considerations of these dominant discourses (Herholdt 1998a; 1998b).

The second objective was to be, as a narrative researcher, part of the "story development" process through which different alternative, more holistic stories of care could be explored.

2.3 RESEARCH PARADIGM AND METHODOLOGY

Black women in historically disadvantaged communities in South Africa have suffered unimaginable pain, humiliation and discrimination at the hands of social engineering and patriarchal and cultural discourses. I want to ensure that I do not victimize the family of women in my research experience in any way, compounding their burdens. It is therefore paramount that ethical considerations be at the core of any research involving these women who are now also carrying the brunt of HIV infection and caring for the sick and the orphaned.

Ethical principles should guide both the paradigm as well as the methodology chosen. The regulative principles that apply to traditional research methods are limited when applied to narrative research. Consequently, I position myself within a post-modern paradigm. As a contextual liberation and feminist theologian, I argue a narrative approach, as an ethical, accountable approach to undertaking research with oppressed black South African women.

2.3.1 A Post-Modern Epistemology

2.3.1.1 *A Shift From A Modern to A Post-modern Discourse*

The shift from a modern to a post-modern discourse is still in the making. It brings with it new understanding of the self and the world.

Modernity endeavours to objectify knowledge and is characterised by a belief in an objective truth that is knowable and researchable. Gergen and Kaye (1992:167) write that the rationale of modernity is that knowledge enables society to make accurate predictions about cause and effect relations and that this allows mastery over the future: “ ... for the modernist, a good society can be erected on the foundations of empirical knowledge.”

Modernity has also influenced relationships and assisted in the construction of definite power relations. Patriarchal discourse has functioned very strongly in the modern worldview. The father was the head of the family and this was never questioned, or allowed to be questioned.

Post-modern discourse can be elucidated as follows: “Postmodern culture does not abolish modern culture. It is the critical companion or interlocutor of modern culture, and it is both a reaction to and a result of the modern culture” (Rossouw 1993:895,903). Müller (1996:55) writes that post-modernism celebrates an inherent distrust in so-called objective truths as providing hope for society. Post-modernists believe that there are limits to the ability of human beings to measure and describe the universe in any precise, absolute and universally applicable way (Freedman & Combs 1996:21). Therefore it is not possible for a person to find an objective truth that is valid for everybody. Post-modern discourse provokes an attitude of uncertainty. Any attempt to gain knowledge requires continual reflexivity, which underlines the provisional and transitory nature of that knowledge (Lowe 1991:43; Dill 1996:109). Post-modern discourse opens up discussions that question constructs such as gender, culture and patriarchal discourses. Therefore, I chose to approach

these discourses from a post-modern worldview. Since post-modernism allows and in fact encourages multiple truths you can include more stories – instead of one story, one voice, you can have many – which is a way of including the voices of those marginalised by modernist “objective truth”.

2.3.1.2 *Post-modern Discourses*

There was a shift towards post-modern thought when cybernetics, constructivism and social construction discourse became dominant discourses, challenging the notion of a single meaning of reality. Discourse analysts move from a relationship between mind and language to language as a system of social interdependence (Gergen 1992:17).

According to a modernist worldview, we can use language unambiguously to represent external reality, and our internal representations are accurate reflections of external reality. Post-modernists believe differently. They focus on how the language they use constitutes their world and beliefs (Freedman & Combs 1996:28). As Anderson and Goolishian (1988:378) put it: “Language does not mirror nature, language creates the natures we know.” Language in a post-modern discourse has developed in different disciplines, such as post-structuralism, constructivism, social construction discourse and deconstruction.

Post-structuralism evolved amongst French philosophers, including Derrida, Foucault, Deleuze and Levinas (Lechte 1994:95). Post-structuralists suggest that language does more than represent or reflect a reality. Language mediates and constitutes our lives (Kotzé & Kotzé 1997:32). Post-structuralism has influenced the ideas of many therapists such as Anderson and Goolishian (1992) and White and Epston (1990). Post-structuralism therefore influenced the thinking around narrative therapy.

Social construction discourse can be associated primarily with Kenneth J Gergen (1985). Gergen (1985:266) describes social construction discourse as follows: “Social constructionism inquiry is principally concerned with

explicating the processes by which people come to describe, explain or otherwise account for the world in which they live.” Thus knowledge is socially constructed in language. According to Gergen (1985:270), “knowledge is not something people possess somewhere in their heads, but rather, something people do together. Language is essentially shared activities.” Social construction discourse is an attempt to approach knowledge from the perspective of the social processes through which it is created (Kotzé & Kotzé 1997:29). A social construction of knowledge emphasizes the importance of language as a social phenomenon through which individuals as relational being live (Kotzé & Kotzé 1997:30).

Deconstruction developed mostly under the influence of Derrida and Gadamer. Gadamer (Anderson & Goolishian 1988:380) maintains that any linguistic account carries with it a “circle of the unexpressed” which he calls the “infinity of the unsaid”, because no communicative account, no word, is complete, clear and univocal. Gadamer (Anderson & Goolishian 1988:380) also argues that all words carry unspoken meanings and possible new interpretations that require expression and articulation.

Jacques Derrida’s (Sampson 1989:7) efforts to deconstruct Western metaphysics helped to inaugurate the post-structuralist movement. Derrida (Sampson 1989:7) explains that to deconstruct is to undo, not to destroy. Sampson (1989:7) demonstrates how Derrida, in his deconstruction, wanted to undo the tradition that dominated Western thought and formed the roots of understanding by deconstructing the tradition, while at the same time using the tools of that tradition. One of Derrida’s central methodological devices is to place a term under erasure. A word is literally first written and then erased, simultaneously keeping both the erased word and the word itself. Words used are therefore necessary in order to understand, while they are at the same time inaccurate (Kotzé & Kotzé 1997:34). Within the meaning of any possible text, there is also its opposite text (Sampson 1989:8).

Chang and Phillips (1993:100) quote Anderson and Goolishian’s definition:

Deconstruction ... is to ... 'take apart the interpretive assumptions of a system of meaning that you are examining ... [so that] you reveal the assumption on which the model is based.' [As] these are revealed, you open space for alternative understanding.'

This research is based on the concept of deconstruction in general, and the deconstruction of gender, culture and the patriarchal discourse in particular, which is linked with the deconstruction of power and power relations. The term *discourse* is a central concept in post-modern thought (Gordon 1980; Lowe 1991) and does not refer to language or social interaction, but to relatively well-bounded areas of social knowledge (McHoul & Grace 1993:31). The term discourse is used, firstly, to indicate a process of conversation through which meanings are constituted and, secondly, to refer to systematic and institutionalised ways of speaking/writing or otherwise making sense through the use of language (Lowe 1991:144,45). Discourses as the dominant texts or bodies of knowledge marginalize some voices and privilege other 'knowledgeable' voices and thereby constitute power-knowledge relations (Kotzé & Kotzé 1997:35). Therefore, a dominant discourse such as patriarchal discourse can be deconstructed within a post-modern social constructionist worldview.

2.3.1.3 *Language and Discourse*

Both the constructivist and social construction approaches emphasize the importance of language (Kotzé & Kotzé 1997:30). Constructivists Maturana and Varela (1992:246) use the term 'linguaging' to explain how social structural coupling between human beings comes about. In social construction discourse, the expression "to be in language" (Anderson & Goolishian 1988:377) is used to explain that language is a dynamic, social operation and not a simple linguistic activity (Kotzé & Kotzé 1997:30). People exist in language, because meaning and understanding come about in language.

It is through language that meaning is created, yet it is not in language *per se*, but through the way language is used in a discourse or conversational manner that it becomes constitutive of our reality (McLean 1997:14). The post-modern emphasis in social construction discourse is not primarily on language, but rather on discourse (Kotzé & Kotzé 1997:31). The various discourses in society have a constitutive or shaping effect on the personal discourses and lives of people.

Patriarchy is a dominant discourse which has constituted the lives of many people. Patriarchy encapsulates the mechanisms, ideology and social structures which have enabled men throughout much of human history to gain and to maintain their domination over women (Ramazanoglu 1989:33). This discourse has been widely accepted by women and children, and has seldom been questioned. Women and children were disempowered and marginalized through this discourse. Oppression and violence against women (and children) – wife battery or beating – is rooted in and is the logical conclusion of basic patriarchal assumptions about women's subordinate status. Patriarchy has constituted and influenced many relationships and the lives of people by reinforcing such assumptions.

2.3.1.4 *Power and Discourse*

In the discussions surrounding power and family therapy, the work of Foucault plays a most important role, because he examines discourses that entrench power and power relations. Foucault (Gordon 1980:141) explained that 'power is *always already there* and that one is never *outside* it.' Power and power relations can be seen in everyday interactions, techniques and practises, such as the establishment of hierarchies of individuals in relation to one another (Parker 1989:58).

To Foucault, power is knowledge and knowledge is power (Gordon 1980). Language is an instrument of power, and people have power in a society in direct proportion to their ability to participate in the various discourses that shape that society (Freedman & Combs 1996).

He [Foucault] argues that there is an inseparable link between knowledge and power: the discourses of a society determine what knowledge is held to be true, right, or proper in that society, so those who control the discourse control knowledge. At the same time, the dominant knowledge of a given milieu determines who will be able to occupy its powerful positions.

The operation of power, however, exists outside the individual's locus of control, for the systems of power recruit people into collaborating in the subjugation of their own lives (White & Epston 1990; White 1992:138). White (1988/9, 1992, 1998), following on from Foucault, writes that we tend to "internalize" the "dominant narratives" of our culture, easily believing that they speak the truth of our identities.

Patriarchal discourse has given power to men in our society, while women and children have been subjugated by this power. Thus, patriarchy refers to male domination, to the power relationships by which men dominate women, and characterises a system whereby women are kept subordinate in a number of ways (Bhasin 1993:3). This discourse has become a dominant narrative which has been internalised by those people who are marginalized by it, because they think that it is the way things should be. In the past and even in the present, men have had all the power, thus all the knowledge. Women and children were not allowed to question men's knowledge or their power, because the father ruled the household (Bhasin 1993:3). By deconstructing this power discourse, we open up space for alternative understanding and for the 'unsaid' or the 'unexpressed' (Anderson & Goolishian 1988:380) of this discourse.

2.3.2 Theological Stance

Theology and practical theology play an important role in this research. Modern theologies have kept discourses on gender, culture and patriarchy alive in our communities. The theology of the Dutch Reformed Church in

South Africa to a great extent still condones and reinforces discourses embedded in white, westernised theology.

Maimela (1996:173) argues:

... in order to make this exploitative sexist domination work and be respectable patriarchal societies [men] coopted religion for the express purpose of justifying the subjugation and oppression of women ...

Religious traditions were relied upon to provide an underpinning for social norms. The shift, however, from a modern to a post-modern culture, a shift which is still in the making, obviously requires new theological reflection, because it brings with it a new understanding of the self and the world (Rossouw 1993:895).

2.3.2.1 *Theology*

Theology is a '*logos*', a word about '*Theos*'. Theology is a scientific study. God, however, cannot be the object of scientific study; nor can God be captured in human language (Heyns & Pieterse 1990:3). Therefore theology could be defined as a scientific study of people's faith in and their religious statements about God (Heyns & Pieterse 1990:3). We could ask questions such as the following: 'How can we come to know God?' or 'What is knowledge of God?' Kotzé (1992:16) writes that the term theology points to knowledge of God. If knowledge is scrutinised, from a post-modern epistemological point of view, it can be described using two perspectives: constructivism regards knowledge as a human construct; social construction discourse describes knowledge as a social construct. Thus I consider theology both as a human and a social construct about God and how people associate these constructs with their lives.

What, then, is the object of theology? König (1973:14) writes that theology works with the entire reality '*coram Deo*', being the entire reality before the face of God. Kotzé (1992:17) responds that theology is not only a study of

God as the object of theology, but theology is also a study which attempts to obtain a specific perspective on the entire reality in its relatedness to God or God's relatedness to the entire reality. Thus theology can be regarded as a body of human and social constructs of the entire reality, because we as human beings stand in relation to the entire reality and the entire reality stand in relation to God. This will be important when we talk about pastoral therapy and God's involvement in every session.

2.3.2.2 *Post-Modern Theology*

Discourses embedded in gender, patriarchy, and culture that render women infected/affected by HIV/AIDS powerless to make decisions about care are challenged by post-modern theology, which is, in a sense, a rediscovery of the value of human participation and a quest for wholeness and meaning (Herholdt 1998a:218). Post-modern theologians prefer qualitative methods, meaning that post-modern theologians tend to be more interested in the patterns produced in society than in attempting to produce abstract definitions (Herholdt 1998a:220).

A post-modern approach to practical theology and thus pastoral therapy needs to be holistically integrated with the task of social transformation (Gerkin 1997:74). In pastoral therapy, the prophetic tradition offers an alternative perception of reality (Brueggemann 1987:110). The prophetic tradition, according to Gerkin (1991:163), displays sensitivity to human need, human frailty, and the problems of humans ensnared in deception. In terms of my research, the most useful aspects of the prophetic tradition are its concern for justice, and its awareness of systemic evil and people's dominance of others. The prophetic tradition in pastoral therapy is, therefore, linked to the ethical considerations of post-modern theologies. (I will elaborate on the importance of ethical considerations when I explain the choice of my research methodology).

Pieterse (1996:60) argues that 'being in the world' means having to roll up our sleeves and getting into the thick of everyday politics and development. This

view gives a practical slant to Rossouw's (1993:903) demand that people go from 'being right to doing right'. Pieterse (1996:60,61) maintains that, to make this change possible, a post-modern approach gives him the

... tools to deconstruct and expose the inherent oppressive nature of dominant discourses in society, which serve to entrench existing relations of inequality between classes and groups; ... [and allows him to be] more susceptible to being 'playful' along with being committed to 'serious' action, i.e. 'seriously playful' and/or 'playfully serious.'

From a radical post-modern perspective, both the church and Christians have a very important role to play. Pieterse (1996:61) asks a critical question: What is the role of the church and Christians? Pieterse (1996:61) responds that the purpose of the church is

... to fulfil an interlocutor role in creating spaces for different groups to share and express subjective understandings with a view of fostering critical alliances; ... to provide a caring and supportive environment for her members who struggle with the complexity and tiring consequences of political practise at the margin

Ever since I could remember, I wanted to be a minister of religion. A strange calling, it seemed, given the fact that the Dutch Reformed Church did not ordain women at the time. In retrospect, my mother contributed considerably towards my calling by deconstructing power discourses in society. She reminded me constantly that in Christ neither gender, race or culture, nor status, determine the value of a person. I therefore believed that I could challenge viewpoints different from my own, no matter who spoke them.

These beliefs have brought me into conflict with the 'powerful' in my community since an early age. I challenged the Principal in primary school for the disrespectful way he addressed pupils and I refused to participate in corporal punishment. I confronted the Minister for expecting me to learn the Ten Commandments by heart as a prerequisite to be accepted as a member of the congregation. I challenged school rules that strengthened patriarchal

discourse. The 'powerful' assured my mother that I was going through a phase of teenage immaturity, a discourse embedded in patriarchy, silencing the voices of teenagers.

Before enrolling for a BA (admission) at the Rand Afrikaans University, I visited my congregation's Minister to share the excitement of my decision to study theology. He tried to convince me to change my study direction, "... as this is no job for a woman." The theology class of 1992 consisted of three female students and seventy-eight male students. Ironically, the top achievers throughout my student career were mostly women. But then again, the gendered discourse states that women may achieve high grades at school and university, but they would never be able to compete in the 'real' or 'outside' world.

Herholdt (1998a:218) states that post-modern theology aims to provide fresh insights, answer existing anomalies and provide new meaning by moving beyond modernism. Thus post-modern theology displays greater openness to non-conceptual ways of knowing. In post-modern theology, a believer is not called upon to master abstract truth, as in modernist discourse; instead the believer is challenged to make sense of the world by participating in the creation of a new world in terms of which the self can be redefined.

With its emphasis, therefore, no longer on dogma, which focuses on the rules and regulations of the church, but on the ethical implications of such rules and regulations on the lives of human beings, post-modern theology underpins my epistemology.

I don't want to go into a detailed description of post-modern theology as many theologians have already written about it (Davaney 1987; Griffen 1989; Peters 1985; Van Aarde 1995; Van Huyssteen 1995 and others). I will, however, discuss those ethical principles inherent to a post-modern theology, which influenced my choice of a theological stance. I will also highlight those aspects of post-modern theology that I regard as applicable to a deconstruction of the discourses embedded in patriarchy, gender and culture.

Post-modern theologies focus renewed attention on the consequences of theological paradigms and a theological understanding of the world. Theologies and Christian practices that cause systematic or prolonged suffering and degradation can hardly be worthy of the name 'Christian' (cf Hart & Nielsen 1990:228). Rossouw (1993:903) uses the phrase 'from being right to doing right', to describe this ethical aspect of post-modern theology. A Christian understanding of the world can never be anti-human. On the contrary, it should always be able to claim that it is the best available approach to ensure the fullest development of human potential in all stations of life (cf Küng 1991:89-98; Richard 1988:94-97). Christians of all denominations should therefore not only be sensitive to suffering in general, but should be especially sensitive to the practical consequences of theological perspectives and practises based on belief. "A kind of faith empiricism is not inappropriate to ensure that orthodoxy is also complemented with orthopraxy" (Rossouw 1998:903). Dogmas have tended to marginalize and disempower many people, effectively silencing their voices.

Rossouw (1993:902-3) writes:

Theology has a long and rich tradition from which it can draw in its response to the challenge to care for the marginalized in society. Liberation theology and the most recent research on the historical Jesus are only two of the recent developments which have again focused on the special concern displayed in Scripture for the marginalized ... God therefore reveals and illustrates through the story of his people and the story of Jesus a special concern for those whose human value and dignity is denied by society – those in danger of dropping out of the care of society, or who have been excommunicated from society.

Post-modern culture challenges the church to be true to its calling. It has a unique contribution and perspective to offer on this issue – a perspective that can enrich the post-modern discourse on marginalisation.

At this point, I want to mention Foucault (Gordon 1980; Fillingham 1993), because he is a post-structuralist who concentrates on ethical issues and relational power. Parker (1989:61) writes the following about Foucault's idea of relational power:

What is spoken, and who may speak, are issues of power. As well as organizing and excluding forms of knowledge, discourse relates and helps organize social relations as power relations.

In a post-modern worldview, it is important to ask the question raised by Parker (1989:61): 'What is spoken and who may speak?' I raise the question in order to explore the ethical implications of an action or discourse. Ethical considerations involve a focus on power relations. Parker (1989:67) contends: "Not only are social relations stressed, and social relations as they are embodied in discourse, but we may view these relations as power relations." McHoul and Grace (1993:39) quote Foucault:

Power is everywhere, not because it embraces everything but because it comes from everywhere ... Power comes from below; that is there is no binary and all-encompassing opposition between ruler and ruled at the root of power relations, and serving as a general matrix – no such duality extending from the top down and reacting on more and more limited groups to the very depths of the social body. One must suppose rather that the manifold relations of force that take shape and come into play in the machinery of production, in families, limited groups and institutions, are the basis for wide-ranging effects of cleavage that run through the social body as a whole.

If power is everywhere, then women and children have power to resist, although they have been silenced by discourses embedded in patriarchy, gender, poverty, government policies, politics and religious beliefs. Post-modern culture insists that those with so-called expert knowledge are not the only ones to whom one should listen when decisions are made.

Those who are affected by such decisions also have a valuable and indispensable contribution to make – even if they are considered non-experts or non-literates in terms of modern rationality. Expertise must be enriched and informed by the experience of those on the receiving side of expert opinion. This post-modern emphasis becomes especially clear in the concern for those who have been marginalised in modern culture – those who have been socially rejected by modern society and those who are not fit to compete in modern society (Rossouw 1993:902).

Post-modern theology is concerned with the ethics of our day-to-day lives, and not with the dogma of 'being right'. Patriarchal discourse has involved, for many years, a misapplication of dogma, resulting in a negative influence on many people and a marginalisation of many voices. Post-modern theology leaves a door open to deconstruct discourses embedded in patriarchy, gender, poverty, government policies, politics and religious beliefs as a result of its emphasis on relational power and ethical considerations – to do right instead of being right. Post-modern theology has influenced my thoughts about dogma and ethics, and opened my mind to listen to people's lived experiences; instead of the theories and dogmas that I was taught were the only way.

2.3.2.3 *Practical Theology*

A narrative approach, for which I will argue my case later (see 2.3.3.2), must be contextualised in practical theology, because pastoral therapy is one of the operational fields of practical theology. Therefore, it is necessary to situate this research in a practical theological approach which corresponds to the epistemology and the post-modern theology of this research. Practical theology focuses on people's religious actions, with the emphasis on the word 'actions' (Heyns & Pieterse 1990:6). Gerkin (1986:61) defines practical theology as follows:

Practical theology, as here conceived, is the critical and constructive reflection on the life and work of Christians

in all the varied contexts in which that life takes place with the intention of facilitating transformation of life in all its dimensions in accordance with the Christian gospel.

Practical theology is thus a reflection on the actions of Christians in their everyday lives. It is the application of the Christian theology to the everyday.

A narrative hermeneutical approach (Gerkin 1986), an eco-hermeneutical approach (Müller, 1996) and an approach called a 'communal constitution of knowledge' (Dill 1996) are described as possible practical theological approaches for this research. Contextual, liberation and feminist theology contain elements which inform these approaches.

There are five main approaches in practical theology. Burger (1988:84) identifies three, namely a confessional approach, a correlative approach and a contextual approach. Dill (1996:114,115) postulates two more approaches, a hermeneutical approach and a constructivist approach.

The roots of these dominant models for practical theology in South Africa lie principally in the Netherlands and partly in Germany and the United States of America. The major Afrikaans-speaking universities, the universities of Stellenbosch, the Orange Free State and Pretoria, have for many years enjoyed a virtually unchallenged hegemony over the discipline of practical theology in South Africa. Taxpayers have, over the decades, funded the training of mainly male ministers for the Dutch Reformed family of churches in faculties staffed by white men.

Minority voices have been heard from some of the English-speaking universities and seminaries. These theologians belong more to correlational or contextual schools of practical theology. A third grouping is found at the University of South Africa. Here greater emphasis is placed on empirical research in a more operational and communicative approach to practical theology.

The “socio-economic pattern of contextualisation” described by Bosch (1991:421) as “evolutionary or revolutionary”, convinced me to ‘doing’ theology. Contextual theology claims to be an epistemological break from traditional theologies designed to serve the interest of the West. It is affirming justice against oppression, shifting from the general to the local, co-constructing a variety of “local theologies” (Bosch 1991:426) and opposing a Western theology claiming universal validity. This necessitates self-other actions that go beyond the luxury of merely thinking commitments, to doing commitments. It is committed to the poor and the marginalized; it is based in the notion that theology can only be done with those who suffer. It emphasises doing theology since doing is more important than knowing or speaking (hermeneutic of the deed) (Bosch 1991:424).

A participatory approach to practical theology is practised against the backdrop of the postmodern paradigm that sees “theology as a commitment to participation” (Herholdt 1998:24) which goes beyond the doing of theology. Within this approach I see “practical theology [as] practised/done by *all* people grappling with an understanding of the presence of the spiritual, holy, ‘Other’, or God in our human circumstances” (Roux et al 2001:64).

Ackerman (1996:34) defines a feminist theology of praxis as the “critical, committed, constructive, collaborative and accountable reflection on the theories and praxis of struggle and hope for the mending of creation based on the stories and experiences of women/marginalized and oppressed people”. I identify with Ackerman’s feminist theology of praxis in which the notion of a ‘liberating praxis’ is a central concern to the present South African context. “Liberation is a process in which oppressive groups acknowledge their responsibility for structures of domination and name the forces that lead to repentance and conversion (Welch 1990:157)”.

The actual stories of women infected/affected by HIV/AIDS (struggling against gender and cultural oppressions) are an important source for my reflections on caring. Liberating praxis is collaborative, sustained action for justice, liberation and healing, empowered by continuous struggle, hope and passion.

It can emerge from those who have privilege and power as well as from the actions and knowledge of those who are marginalized and oppressed.

Clearly, not all models of practical theology are liberating. The resources offered by feminist theologies are not apparent in the different schools of practical theology in South Africa (Chopp 1991). In this country, the relationship between knowledge and power in the history of minority rule illustrates this point (Jansen 1991). The bond between the white Dutch Reformed Church and the Nationalist Party served the cause of white rule. The Ministers for this church had to be 'properly trained' so as not to rock the ideological boat.

It was only as a student that I was introduced to the thinking of doctor Beyers Naudé, ostracised anti-apartheid theologian from the Dutch Reformed Church. His talk at the University of Pretoria spurred me to start reading about my "dark" past, as being a white person who benefited immensely from the racial segregation system, purely on the basis of my skin colour. Racial discrimination also opened my eyes to gender discrimination growing up in a patriarchal society. Both were inimical to my belief in the dignity and worth of all people. Both called for resistance.

In Dill's (1996) overview of the hermeneutical- and constructivist approaches, he comes to the conclusion that these approaches, although they are essentially modernist, show signs of the emergence of a new paradigm and thus a new epistemology. Post-modern narrative social construction discourse, however, does not slot neatly into one of these five approaches. Therefore I choose a narrative hermeneutical practical theology, which Gerkin (1986:59) describes as follows:

Narrative practical theology is, therefore, an ongoing hermeneutical process within the immediate storied context of ministry. The intention of that process is the transformation of the human story, both individual and corporate, in ways that open the future of that story to creative possibilities.

Within the South African context, Müller (1996:5) has developed a definition to comply with the expectations of a broad eco-systemic paradigm. He describes Practical theology as the systematically-structured, ongoing process, by which the aim is to enlighten and renew human actions that are inherent in the Christian faith tradition.

Practical theology, seen from a narrative hermeneutical perspective, involves a process of the interpretive fusion of the horizons of meaning embodied in a Christian narrative with other horizons that inform and shape perceptions in the various arenas of activity in which Christians participate e.g. contexts, time, location and tradition (Gerkin 1986:61). According to Gerkin (1984:45-47), Gadamer's concept of fusion of horizons implies that within pastoral therapy there is a bilateral understanding process between the two subjects; the person's own pre-understanding must be heard and a new narrative with new meaning has to be created. Any attempt to understand the other person must therefore necessitate the creation of new meanings and alterations. Thus, pastoral therapy becomes, according to Gerkin (1984:47), a meeting between narratives. In the gap between my own pre-understanding of what I am about as a pastoral therapist – what I hear, and see, and look for – and the other person with her or his own pre-understanding of what the problem is and what is needed, lies the arena in which the Spirit may be expected to be active.

People live *coram Deo* in contemporary events in time and are engaged in an ongoing process of generating new metaphors and disregarding old metaphors while holding on to the scriptures (Botha 1998:120). Gerkin (1986:48) adheres to the notion of an open-ended historical process:

The biblical story of God is an open-ended story. It does not stop with the end of the collection of biblical texts. Rather it concerns the activity of God in all of history, a story that continues in the present and is to be fulfilled in the future.

Thus the story of God and the story of human beings are in conversation. This is then a hermeneutical process through which new meaning is created. Since the story of God is an open-ended story (Gerkin 1986:48) then we as human beings are creating new meanings 'in language' with God every day. Gerkin is still confessional in his narrative hermeneutical approach, however, as he still emphasises the horizon of the confessional tradition as the platform by which fusion is undertaken with the horizon of a person's own narrative.

Therefore it is necessary to also include the approach proposed by Dill (1996:224-225) for practical theology, an approach that is based on post-modern social construction discourse as epistemology:

In my research, I have shown ... that the enormous epistemological dilemma of modernism, i.e. subject-centred thought, has also influenced practical theology. The dilemma is that modernist man relies primarily on his rational insights to achieve knowledge ... and does not consider the broad context sufficiently. This leads to serious reductionism and an attenuation of possibilities. Over and against this limited epistemology, I propose a postmodernistic epistemology of the 'communal constitution of knowledge.' Gergen's social construction theory is the basis of this epistemology and I build my proposal for a new basic theory for practical theology on this epistemology.

The communal constitution of knowledge is a new course for the process of conversation. Thus all traditions are social constructions and not a single one can claim the truth over others. Therefore, the communal constitution of knowledge using social construction discourse as a basis is an attempt to approach knowledge from the perspective of the social processes through which it is created, or the social processes that are constituted in the community.

I would, however, like to include an element of the prophetic pastoral practise proposed by Gerkin (1991) and the political-critical current suggested by Heitink (1999:174). In practical theology, the focus was, until recently, on the hermeneutics of the confessional truth. Critical questions were seldom asked

about the practical consequences of these theological perspectives and practises based on belief.

In practical theology we have to shift from a hermeneutical tradition to a more political-critical current. Heitink (1999:174) quotes Otto who describes practical theology as “a critical theory of a religiously mediated praxis in society.” According to Heitink (1999:175), two themes are central: the knowing subject and the ideological and historical-practical impact of theories and practices. This demands a critical approach to ideology and praxis to raise awareness of the need for solidarity. Heitink (1999:175) prefers qualitative action research, where the aim is not just an increase of knowledge, but also a change in the oppressive situation of those with whom researchers establish a close bond. In this sense, practical theology proceeds from post-modern theology, which emphasises ethical considerations.

Gerkin (1991) regards the pastoral prophetic role as important for a transformative vocation for Christian people in the world. Prophetic ministry consists of offering an alternative perception of reality (Brueggemann 1978:110). The prophets took care of the moral life of people in the Bible (Gerkin 1997:110). Gerkin (1997:84) also states that “to care pastorally for the people, was to consistently inquire about and help the people to consider the morality of their actions.” Therefore, a pastoral prophetic role has to be inquiring and assist people to take responsibility for their actions and to be accountable. I regard a prophetic role as important for this research project, because a pastoral prophetic role questions dominant discourses in society. A prophetic role challenged me to question dominant discourses, to consider the consequences of such discourses and to be transparent and accountable towards the participants in the research. As such, a prophetic role and a political-critical current played an important part in this research project.

2.3.2.4 *Feminist Theology*

Feminism originally meant ‘having the qualities of females,’ but in time it became identified with a movement of the liberation of women (Keane

1998:122), a movement that strongly questions patriarchal discourse. Patriarchy perpetuates a system of male domination at the expense of women. Within a cultural-religious context, it became inevitable that patriarchy would reach the momentous conclusion that the domination of wives by their husbands is something of which God approves. The ideal for women, therefore, was one of total servility, meekness and submissiveness (Maimela 1996:17). Reformist feminist theologians recognize patriarchy as a clearly 'universal political structure, which privileges men at the expense of women' (Keane 1998:124) which can, therefore, never be condoned.

One of the chief aims of feminist theology is to correct such imbalances by promoting an alternative way of looking at life, taking seriously woman's giftedness and women's experience (Keane 1998:122). Furthermore, Keane (1998:122,123) points out that the task of feminist theologians today is to criticize abuses within the church which seriously affect women, because abuse and sexual violence are viciously intertwined with patriarchy. Bloomquist (1989:62) argues that violence against women can be seen as an outgrowth of patriarchal social constructs and domination. Poling (1991:13) challenges religious leaders to decide whether to collude with the dominant culture as sanctioning agents of abusive power or to be prophetic critics of the way power is distributed and defined. Poling (1991:23) argues that men have resources they can and do use abusively to exploit the vulnerabilities of women in a patriarchal society. When the oppressions of age, race and class are added, the possibility of an abuse of power is increased.

Seen from a feminist perspective, we are called upon to be like Jesus, we are called 'to a radical activity of love, to a way of being in the world that deepens relation, embodies and extends community, passes on the gift of life' (Ackermann 1996:47). A feminist theological perspective believes that the mending of creation rests on transforming our relationships with ourselves, with one another, with God and with our environment through actions for justice and freedom, as well as changing those societal structures which perpetuate economic, political and social separateness among people

(Ackermann 1996:47). Christianity has in it the seeds of an alternative theory, a theory of liberation, equality and dignity for all persons (Ruether 1989:40).

Feminist theology must be described in more detail for the purpose of this study since feminist theology differs from other theologies in its conscious decision to take a stand for the full humanity of women, children and also for everyone that suffers from male domination and oppression. Feminist theologians strive to bring out an alternative story of Christianity, a story of liberation, justice, equality and dignity. This is also the story of deconstruction, the 'not yet said', an alternative story to dominant patriarchal discourse. In place of patriarchal discourse, feminist theologians hold on to a radical activity of love, which resonates with post-modern theology's ethical considerations. Griffen (1989:8) states that post-modern theology is supportive of feminist or post-patriarchal theology. There are several documents on feminism and feminist theology (Brown & Brown 1989; Lather 1991; Schneir 1995; Trask 1986), which describe the influence and consequences of patriarchal discourse.

Feminist theology was introduced to me in the form of a single assignment in my final year. It was only after two years as a youth pastor in the church, that I started to comprehend the necessity for a feminist theology (Isherwood & McEwan 1993:87) that exposes the harmful effects of a hierarchical model in religions, while enhancing an egalitarian model.

Gender stereotyping caused friction with my colleagues (all male) and their wives. My male colleagues would greet each other with the hand and would wave an informal 'hello' to my side at meetings. During tea breaks at meetings, all eyes turned to me for pouring tea. Needless to say, I refused to do 'domestic tasks' at the church or greet anyone who didn't greet me properly. This stereotyped me as someone who deemed herself better than the wives of the other Ministers. They are God's servants who would continue with the demeaning tasks I refused to do.

I was asked to do a sermon on Women's Day at our church one year. A few older congregational members confronted me after my sermon for preaching a heresy as the Bible clearly teaches that women should be submissive to their husbands.

A female elder once prayed before my sermon: "Dear God, this is only a woman. Fill her with your Holy Spirit to preach the word." Some congregation members would walk out as soon as I mounted the pulpit. I was in desperate need of feminist practices that seek "justice, peace, healing and wholeness for all in partnership" (Ackermann 1991:96). I needed to criticize the abuses in the church, which seriously affected me and simultaneously offer a different interpretation of Christianity.

Post-modern and post-structuralist feminism "view the world as endless stories or texts, many of which sustain the integration of power and oppression and actually constitute [women] as subjects in a determinant order" (Olesen 1994:164). Women are marginalized and oppressed by the stories told by them and about them. I wanted my research journey "to respect women in the research process and give voice to the voiceless" (Olesen 1994:169). My research therefore needed to acknowledge the stories told by the women whilst simultaneously deconstructing the power relationships inherent in these stories.

Feminist theology represents a radical critique of patriarchal religious and theological thinking ..." (Isherwood & McEwan 1991:61). Of course, feminist theology also takes into account ethical considerations. Feminist theologians and ethicists all over the world are examining phenomena such as poverty and HIV/AIDS from a feminist viewpoint. Griffen (1989:8) states that post-modern theology is supportive of feminist or post-patriarchal theology. It is within the community of feminist theologians where I found food for my soul and thought.

Contextual liberation and feminist theology motivated me to found Heartbeat. I longed for children and women to have a platform to voice their stories and to

be given the chance to create their own alternative stories. Heartbeat is my vehicle for a hermeneutic of deed.

2.3.2.5 *Womanist Theology*

I set foot in a township for the first time in 1999 as part of my efforts to initiate the activities of Heartbeat. I was twenty-nine years old and this would be my first encounter with a black township community socially engineered by the apartheid government. Research has shown that the women who have suffered the most are black and poor. They have endured a triple dose of discrimination on the basis of gender, race and social status (Keane 1998:131).

Although a new peaceful democracy dawned on South Africa in 1994 and a handful of women were appointed in Parliament, and although a constitution that enshrines women's rights has been adopted, women in the townships shared their plight with me as unchanged and unchallenged. Hierarchical systems as well as cultural and religious practices render African women voiceless and powerless. Their poor economic status further exacerbates their situation.

HIV/AIDS adds an extra burden of care on their worn-down shoulders. This is sanctioned not only by gender discourses but also by Government policies that place the responsibility of caring for the terminally ill on 'the community' – the women. Women's identities are being reduced to carers of the sick, the weak, the abandoned, and the orphaned.

I traced the story of black women's theologies as I was constantly aware during my research that I am a privileged white South African woman, doing research with black impoverished South African women of a different culture.

The story of black women's theologies had its origin in Womanist theology which was born in North America, where black women took up the gauntlet, especially since their problems, their hopes and their fears did not feature

prominently in the white middle class feminist agenda, or, for that matter, in the Black Liberation Movement under male leadership. Rosemary Radford-Ruether (1975:25) writes: “The Black and the Feminist Movements have betrayed the Black Woman”. In 1979, the black feminist writer, Alice Walker, coined the word womanist. It had its roots, she said, in black folk culture, for “womanish” was an expression used by mothers to describe daughters who were courageous, outrageous and willful (Tuttle 1986:325). Womanist refers therefore to a liberation and empowerment discourse distinguished from white women’s feminism.

Womanist theology then refers to a theology by black women, for black women which challenges the patriarchal oppression unique to black women. Mercy Amba Oduyoye (1988:xvi.), a Ghanaian, writes: “Jesus bears in his person the conditions of the weak and hence those of women. However, African women warn that it is vicarious suffering, freely undertaken, which is salvific, and not involuntary victimization.” For Oduyoye, Christianity resides not in allowing oneself to endure victimization but in being compassionate, sharing the suffering of those who are marginalized by society. The common course or “sisterhood” is seen as primary to womanist theology. Furthermore, the movement is cyclic and democratic – as opposed to the pyramidal structures of male hierarchical models. Womanist theology is also mission-minded. They wish to share their truth with their Third World sisters and to learn from the Third World (Keanne 1998:133). Katie Cannon writes: “Third World women theologians are long suffering custodians of truth. As outstanding pioneers in the struggle for a globally inclusive church, they are protesting against an uncompleted Christianity” (Oduyoye 1988:vii). Cannon believes that Christians are obliged to co-operate with the forces of good and are bound to avoid collaboration with evils such as patriarchy.

2.3.2.6 *African Women’s Theology*

Landman (1998:137) distinguishes African Women’s Theology from Womanist Theology since Womanist Theology is practiced mostly in North America where black women have a different situation and agenda to black

women in Africa. African Women's Theology addresses the specific situation of black women in Africa, the situation that I am also investigating. Landman (1998:137) argues:

The main issue in African Women's Theology centres around redefining the nature of theology in terms of African women's experiences and re-analysing the relation between traditional theology and culture with reference to patriarchy as an unhealthy contact point between the two.

Mbiti (1998) discusses the Bible, the Christian heritage and African culture as sources and tools for theology in Africa. The latter needs further attention. African culture, in the broad sense, includes African religion, world-view and values. In particular, it is African religion, which has been the most influential force in shaping an African world-view. It is still a strong factor today, which surfaces in times of crisis. "The vocabulary used in churches, the spirituality of the people, the translations of the Bible, pastoral problems, health questions and major life situations (like birth, marriage and death) are all heavily coloured by African religion" (Mbiti 1998:150).

For a long time, the main difference between men's and women's theologies was that male theologians took as their point of departure dogmatic principles, while women concentrated on real life stories as the substance of their theologies. Consequently, according to Landman (1998:138), women theologians were criticized for basing their theologies on "stories from the countryside" and thus for a lack of a philosophical based methodology.

African women's theologians have, in the meanwhile, made an important contribution in the field of methodology by insisting on drawing the "intuitive, the poetic, the lyrical" into theology (Ortega 1995:viii). African Women's Theology acknowledges an integration of mind and body, of philosophical thinking and experience, of academia and activism. Their theology is not dependent on the philosophical meta-language of traditional theologies, but on the language of storytelling, stories which testify to hope as well as to anger, to laughter and sorrow alike, to liberation and to oppression.

One of the special contributions of African Women's Theologies is their emphasis on story-telling ministries as healing ministries. In these ministries not only the healing of the voiceless, the poor, the powerless and those at the bottom of the hierarchical ladder is at stake, but also the healing of the breach between soul and body, mind and body and other traditional dualities. Healing comes through telling one's story and listening to the previously muted voices of women who are harassed by unfriendly systems and customs.

Denise Ackermann (1996) notes that the value and place of historically and contextually rooted stories in a feminist theology of praxis, are accepted as the point of departure for doing theology which is concerned with human suffering and emancipation. Practical post-modernist theology which insists on doing right rather than being right is in line with African Women's Theology where story telling is part of the doing.

African women's theologies direct their theologies almost exclusively towards the official scriptures of their traditions. Christian African women's theologies are, for instance, primarily Bible-orientated. The stories of people, especially women, in the Bible, bind women from a variety of cultures in Africa together and provide a common source for their healing.

The ethical question of who is practicing the theology came to the forefront in my study. As a privileged white South African theologian, I can easily identify with a white feminist agenda. However, my life work as well as this research project, centres mainly, but not exclusively, on the real life stories of black South African women and children. Although Landman (1998:138) categorizes both Oduyoye and Ackermann as African women theologians, I struggle with the ethics of such a generalisation. Women in Atteridgeville, where my research was conducted, hardly perceive me as "African". For these women, an "African" woman is defined as a "black woman with a culture different than that of the whites." Therefore, while I may perceive myself as an "African" woman, these women participating in my research do not. Instead, my "whiteness" is paramount in their defining of me.

As such, the discourse on African women's theology pleads to be deconstructed to allow for a definition of a white African feminist theology which "is not dependent on the philosophical meta-language of traditional theologies, but on the language of storytelling" (Landman 1998:138), and which includes the life stories of black women. I cannot speak on behalf of black women, as that would be presumptuous and unethical. I am however, ethically responsible to deconstruct the racial discourse of power and to create the opportunity for my black oppressed sisters to tell their stories in their own voices. I wanted to open a space in my research where the women in the research experience could share their stories of care and or the lack of care. (See appendix 8 for my own attempt as a white woman to construct an African identity.)

2.3.2.7 *Pastoral Therapy*

'Pastoral' (poimhn, poimainw) and 'therapy' (qerapeuw) are both Biblical terms (Botha 1998:147). Pastoral (poimhn, poimainw) means 'to be a shepherd' (Liddell & Scott 1989:652). The shepherd metaphor is also a Biblical metaphor for God as our Shepherd. As the Shepherd, He protects His flock and He is involved with each member of the flock. This returns us to the *coram Deo* concept, implying that God is involved in every therapy session, in every human being's story or narrative, and not only for those who believe that God is their God and that He/She exists.

Therapy (qerapeuw) means 'to do service, to serve, to heal or cure' (Liddell & Scott 1989:362). Although some might use the term 'therapy' in a modern discourse, I prefer to use it in a post-modern discourse. Therapy, and hence therapeutic conversation, entails an 'in there together' process. People talk 'with' one another and not 'to' one another (Anderson & Goolishian 1992:29). The therapist and the person who wants therapy go into a conversation together to find the person's preferred reality and not the therapist's. Both are involved in the healing process and God is involved from a *coram Deo* position. I also like the translation of the term 'therapy' as 'to serve', because

a therapist serves the person who needs help, and this is what Jesus Christ's example was, to serve people.

Modern discourse and positivist theology place pastoral therapists in a superior and therefore powerful position (Dill 1996). A pastoral therapist has to correct a client if she or he is outside the boundaries of the fixed agenda, according to such positivist theology (Botha 1998:152). Theology reacted to and embraced a positivistic methodology, which has led to foundationalist theology. Foundationalist theology claims that a pastoral therapist is an expert on the Bible. The therapist's expertise thus jeopardises the power relationship between pastoral therapist and client. In foundationalist theology the pastoral therapist and client are not free equals since the knowledge of the pastoral therapist becomes a source of power for the pastoral therapist's power who therefore controls the relationship (Botha 1998:152).

A narrative approach to pastoral therapy may change the hierarchical relationship in therapy (Botha 1998:154). The client is seen as the expert of her or his life, ensuring that the therapist is no longer an untouchable expert (Anderson & Goolishian 1992:29). Post-modern social construction discourse insists that people with 'expert' knowledge are not the only ones to whom one listens when decisions are made. A narrative approach in pastoral therapy is one of the possible approaches which could situate itself within post-modern social constructionist discourse as epistemology.

2.3.2.8 *Narrative Therapy*

Post-modern approaches to therapy focus on the client's narrative. The narrative world view proposes that human beings are interpreting beings and that we are active in interpreting our experiences as we live our lives (White 1995b:13). According to White (1995b:14), a narrative perspective proposes that we live according to the stories that we have about our lives, that these stories actually shape our lives, constitute our lives and that they 'embrace' our lives.

Freedman and Combs (1996:31) suggest that when therapists listen to people's stories in order to 'make an assessment' or 'take a history of the illness' or 'offer an interpretation,' they are approaching people's stories from a modernist, 'structuralist' point of view. However, within a post-modern social constructionist world view, it is important to attend to cultural and contextual stories as well as to individual people's stories. I agree with McLean (1997:17) that an individual's stories are influenced by the social, cultural, political and economic environments in which the individual lives. Freedman and Combs (1996:32) quote Mair in this regard: "Stories inform live. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place".

Narrative therapy is therefore also about retelling and reliving stories. As people retell their stories in therapy, they often "notice that they have already experienced participating in an alternative story" (Zimmerman & Dickerson 1996:235). I approached the women who participated in the research with intense curiosity about their "local knowledge" (Freedman & Combs 1996:33). I wanted to listen and develop an understanding of the influences of the dominant stories in their lives. I tried to invite them to celebrate their differences and to develop and perform narratives that they prefer around the particularities of their lives.

2.3.3 Listening to the Stories of Women

I am committed to research that will "not only contribute to the transformation of our society through care with the marginalised and disadvantaged, but also address cultural discourses and societal practices that promote injustices" (Kotzé & Kotzé, 2001:viii). I wanted to provide African women in challenged communities, infected and/or affected by HIV/AIDS, the opportunity to share their stories of care and or the lack of care. I aimed to ensure that I applied a research methodology true to the ethical principles of post-modern, contextual liberation and feminist theology (as discussed above).

2.3.3.1 *The Social Construction Discourse*

The social construction discourse is situated within the post-modern discourse and holds that 'the idea that objective knowledge is impossible'; and therefore 'multiple realities are preferred' (Kotzé 1994:21). The post-modern view of knowledge is that 'values infuse all knowing' and therefore "postmodernism typically values diversity, plurality, and choice" (Hare-Mustin 1997:569). Social construction discourse not only provides a lens (epistemology) through which to view the reality of my context and this research experience, but also empowered me to constitute realities in relationships and language. In this regard Gergen maintains that 'the move is from an experiential to a social epistemology' (quoted by Hoffman 1990:3).

This paradigm, then, takes a 'critical stance towards taken-for-granted knowledge' and works from the vantage point that the 'ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific' (Burr 1995:3). The specific cultural context within which women infected and/or affected by HIV/AIDS are cared for and are taken care of and the taken-for-granted ideas that inform this reality would therefore need to be discussed in this construction. Viewed from a social constructionist perspective, culture is seen as a 'social construction about a social construction' (Kotzé 1994:110).

If the aim of social construction discourse is to expand and enrich the vocabulary of understanding, this would then imply that I am responsible for my description because it is my construction. I am therefore also responsible to undertake my research in an ethical way via participatory research with women utilising social reflexive procedures and being transparent about my assumptions.

It is my hope that the social construction of my experience during this research project will enhance the reader's vocabulary and understanding of

the context and realities of care experienced by women infected and/or affected by HIV/AIDS.

Feminist research has been innovative in its choice to study particular groups of women formerly ignored by social science. Feminist researchers use both quantitative as well as qualitative research methods in this endeavour. I studied a black family of women infected and affected by HIV/AIDS in a previously disadvantaged community. I was involved with ethnography and participatory action research, making use of semi-structured and unstructured interviews in my research experience. These methods of research belong to the qualitative paradigm of research.

Qualitative research is a form of participatory research which challenges the traditional notion of the researcher as the expert and blurs the boundaries between 'researcher' and 'researched' (Bishop 1996:228). Attempts are made to acknowledge and reduce the distance between the researcher and the researched and so control the effects of subjectivity (Bishop 1996:27). In qualitative research, the researcher and participant are interdependent in their process (Steier 1991).

My research became "co-research" (Epston 1995) or, as Dixon (1999:45) prefers, "co-search" in the real sense of the word since my beliefs, my preconceived ideas and my personal feelings were challenged. I realised that "hiding the 'I'" is a pretence, a fraud that forces me to hide my passion, to deny who I am, and to pretend that my words are separate from me. Acknowledging the 'I' allows me to reveal myself and my feelings" (Dudley-Marling 1996:36).

Many feminist researchers have written about the ethical and epistemological importance of integrating their selves into their work, and of eliminating the distinction between the subject and the object. My research experience could be best described by the words "total immersion" (Reinharz 1992:69).

Typically, personal experience is irrelevant in mainstream research, or is thought to contaminate a project's objectivity. In feminist research, by contrast, it is relevant and repairs the project's pseudo-objectivity. Whereas feminist researchers frequently present their research in their own voice, researchers publishing in the mainstream journals are generally forbidden to use the first person singular voice. In this research there is no hiding my subjectivity.

Many feminists establish a rapport with the research participants. This notion stems from the ideology that women experience relationships through an ethic of care, and that feminists, in particular, are supposed to be able to establish intimate relations with women because of political awareness. By achieving rapport, the feminist researcher reassures herself that she is treating the interviewee in a non-exploitative manner. "Rapport thus validates the scholar as a feminist, as a researcher, and as a human being. It symbolizes her sisterhood, her interviewing skill, and her ethical standing" (Reinharz 1992:265). As an interviewer, the feminist scholar is concerned not to exploit her research participants by simply using their story but rather to share some of the experience of her participants.

One implication of qualitative research for power sharing between researcher and researched or participant is that the participant benefits from the research project at the time that it is taking place. Furthermore, the participant in the project is, from start to finish, an owner and co-creator of knowledge. This has several implications for the ethics of research in that it addresses issues such as accountability, deceit and informed consent. Most importantly, it corrects the injustice that for a long time underpinned academic research. Minority and disempowered groups became research populations in projects with advantaged academics, while those being studied enjoyed no benefits at all.

I am concerned with how the voices of women are heard, with what authority and in what form. These concerns were central to my research. Much quantitative research has dismissed, marginalised, or maintained control over the voices of others by an insistence on the imposition of research-determined

positivist and neo-positivist evaluatory criteria, internal and external validity, reliability and objectivity (Bishop 1996:230). In my research experience I was concerned that my objectives not determine which stories were voiced-rather that the women participating could tell the stories they wished to voice.

Together with other feminist researchers, I am highly conscious of the absence of women's voices, distortions, and the charge that preparing an account in the usual social science modes only replicates hierarchical conditions found in the parent disciplines, where women are outside the account (Olesen 1994:167).

2.3.3.2 *"In Africa we do things together through stories"*

Narrative research is situated within the broader domain of qualitative social science research. The narrative study of lives is a growing, multidisciplinary tradition of research. The main data collection instrument in narrative research is the research interview, which is often conducted in a naturalistic setting over an extended period of time and might require some significant involvement of researchers in the lives of those they study.

The narrative world view proposes that human beings are interpreting beings and that we are active in interpreting our experiences as we live our lives (White 1995b:13). I aimed therefore to listen to the many stories that constitute the world of South African women, HIV/AIDS and care.

These women live their lives according to the stories that they have about their lives, stories that actually shape their lives, constitute their lives and 'embrace' their lives (White 1995b:14). Freedman and Combs (1996:31) suggest that when therapists (in this case 'researchers') listen to people's stories in order to 'make an assessment,' to 'take a history of the illness' or 'offer an interpretation,' they are approaching people's stories from a modernist, 'structuralist' point of view. However, within a post-modern social

constructionist world view, it is important to attend to cultural and contextual stories as well as to individual people's stories.

White, following on from Foucault (Gordon 1980), writes that power is knowledge and knowledge is power. This implies that those who have power also have knowledge and vice versa. According to this argument the therapist has knowledge (in the form of a university degree but more specifically in his/her mastery of the language/discourse of therapy) and thus has power over the patient in their relationship. Patients and/or research subjects generally lack either the education or the mastery of the language or both and thus do not have control in their relationship with the therapist/researcher. Similar power relations can be seen in everyday interactions, techniques and practises, like the hierarchising of individuals in relation to one another (Parker 1989:58), and form the bedrock of modernist constructions of the role of therapy. Here therapy is about the therapist finding the answer, the objective truth. The therapist thus changes the patient according to this objective truth as discovered by the therapist.

The narrative approach affords a method by which it is possible to be true to the post-modern social-constructive paradigm during research. As Müller et al (2001:67) contend:

For us, the aim of the research is not to bring about change, but to listen to the stories and to be drawn into those stories. While the structuralist researcher has objectivity in mind by trying to be an observer from outside, and by trying to bring about change from the outside, the narrative researcher has subjective integrity in mind and strives for participatory observation.

Within a post-modern social-constructionist worldview, therefore, it is important to attend to cultural and contextual stories as well as to individual people's stories since all stories must be listened to. Importantly as well, all the research companions travel together in the scientific vehicle of social-constructionism. Manaka (2001:5) summarizes this process through the contention that "in Africa we do things together through stories." Social-

constructionism thereby provides a method by which it is possible to combat the hierarchical structure of traditional therapy. Since the researcher is not attempting to bring about change from the objective outside, their position of power is diluted. The process of doing things together goes part way to challenging the powered relationship between the therapist who has the power and the patient who needs the therapist. Doing things together recognises that the therapist needs the patient as much as the patient needs the therapist. Thus, as opposed to the therapist and the patient, social-constructionism refers to ALL of the participants in the process of therapy as co-researchers.

Since the narrative approach is derived from a post-modern social-construction discourse, this has implications not only for the way in which narrative researchers think about truth, but also for the way in which we try to be truthful in doing research. Graham (2000:107) talks about the 'crisis' of post-modernity:

The 'crisis' of post modernity is not simply one of believing, but of revolutions in patterns of work and leisure, use of technology, the exercise of civic power, participation and citizenship, access to resources, relationships to the environment, and the use and abuse of scientific innovations

Narrative researchers such as Müller et al (2001:76-96) argue that the crisis also includes the use and abuse of research and the need to deconstruct the sometimes abusive power relations which saturate research projects. In an effort to deconstruct the power relations narrative researchers choose not to use language such as "research objects" or "research population", but rather refer to them as research participants or co-researchers. This is epitomised by the referred to co-operation between the researcher and those persons (co-researchers) with whom the research deals (see Morgan 2000:3). This cooperation then means that the purpose of the research is not to reach the objectives of the researcher, but should also be meaningful to the persons or groups who form the basis of the research. Research, in this instance, is not about change, but about listening to stories and about becoming "part" of the

stories. The researcher strives towards participating inter-action. Through participation, action is possible which is neither abusive nor victimising.

Viewing the research question from a narrative angle entails stories/events which, in the course of time, are linked together to form a plot (Morgan 2000:5). Patriarchal, gender, and cultural discourses all form part of the stories told. But these discourses have rendered power to men in our society, while women and children have been subjugated by this power. The ideology of 'apartheid' has rendered all black people powerless by engineering their every move. These discourses have become the dominant narratives in South African society and are the lens through which South Africans experience their stories. These discourses will thus saturate the stories individuals tell about themselves. By deconstructing these discourses, space can be opened up for alternative understandings or insights, and the speaking out of those who are marginalized by the discourse.

A narrative approach thus offers useful ideas to facilitate a process in which African women in historically challenged communities, infected and/or affected by HIV/AIDS, can speak out about their experiences of care and or the lack of care. White (1998:1) indicates that the primary focus of a narrative approach is people's expressions of their experiences of life. Winslade and Monk (1992:2-3) argue that:

We live our lives according to the stories we tell ourselves and the stories that others tell about us. Narrative counselling is a deceptively simple therapy. It is based on the idea that we all generate stories to make sense of ourselves and of the circumstances of our lives. However, we are not the sole authors of our stories. Many of the dominant stories that govern our lives were generated in our early experiences of childhood at home, at school, at church, in the neighbourhood.

These stories constitute our dominant way of interpreting and experiencing our lives. These stories also include experiences that do not fit into people's day-to-day lives. These experiences are sometimes told as if they are part of someone's life. People experience themselves as the problem, but, according

to White (1988/9:6), 'the problem is the problem, the person is not the problem.' Externalising the problem opens up fresh ways to talk about the intimate daily struggles of women infected/affected by HIV/AIDS and their experiences of care or the lack of care, without blaming or rejecting them for what the problem has caused in their lives. Furthermore, it gives them a chance to share the stories and experiences that constitute their lives.

The narrative approach therefore relies on Derrida's idea of deconstruction to take apart and analyse the problem-saturated narratives that dominate a person's life (Sampson, 1989:7). Derrida examines and illustrates how the meaning of any symbol, word or text is inextricably bound up in its context. Derrida believes that it is fruitless to search for the one 'real' or 'true' meaning of any text, as all narratives are full of gaps and ambiguities (Freedman & Combs 1996:46) just as all words and/or symbols are full of gaps and ambiguities. According to Wolfreys (1998:50), Derrida argues that being faithful to a text, to any text, means resisting the temptation to impose a single method of reading into all texts. This argument can therefore be applied to the practice of therapy/research whereby the therapist/co-researcher must resist the temptation to search for and/or impose an objective truth on the stories of the patient/co-researcher. Rather than imposing an objective truth/meaning onto the stories of the patient/co-researcher, instead it is important to deconstruct all of the stories which inform the individual's experience. White (1992:121) provides a definition of deconstruction:

... deconstruction has to do with procedures that subvert taken-for-granted realities and practices; those so-called 'truths' that are split off from the conditions and the context of their production, those disembodied ways of speaking that hide their biases and prejudices, and those familiar practises of self and of relationship that are subjugating of person's lives. Many of the methods of deconstruction render strange these familiar and everyday taken-for-granted realities and practices by objectifying them.

Deconstruction thus implies that stories have many possible meanings, and that we have to listen carefully to the 'not yet said', the alternative story that

people do not tell. To listen for what was not said in this sense does not refer to the subconscious or repressed in a psychodynamic sense, but to listen for the opposite meaning within what was said, to validate and to question both what has been said and what has not been said (Kotzé & Kotzé 1997:34). By listening deconstructively to a person's story, a context can be created in which re-authoring can occur.

The discourses which influence an individual's story are multiple and include the social, cultural, political and economic environments in which the individual has lived (McLean 1997:17). The stories we are told about our environment our culture etc shape and influence the stories we tell and the stories we experience as our lives. Freedman and Combs (1996:32) quote Mair in this regard:

Stories inform life. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place.

Bearing this in mind, then, the client in a therapy session has a tremendous amount of knowledge (and therefore power) about their story since it is the client who must tell the therapist about the environment, culture and political environment they inhabit. Anderson and Goolishian (1992) approach therapy with the idea of the *client is the expert* and they adopt a *not-knowing* position. The client and therapist must then work together to deconstruct those stories. The danger in research is that the respondent's stories are "suppressed in that their responses are limited to 'relevant' answers to narrowly specific questions" (Mishler 1986:68). The researcher can direct or limit the story through the questions asked. To allow the stories of people and communities to be fully told, in their own way and to speak in their own voices, the researcher that works from a narrative perspective needs to be in a "not-knowing" position. Adopting a not-knowing position requires the therapist to have a genuine curiosity for the client's story, and always to position herself or himself in a state of 'being informed' by the person. Anderson and Goolishian (1992:29) maintain that

The 'being informed' position is critical to the assumption in hermeneutic theory that the dialogical creation of meaning is always a continuing process. In not-knowing the therapist adopts an interpretive stance that relies on the continuing analysis of experience as it is occurring in context. The therapist does not 'know', *a priori*, the intent of any action, but rather must rely on the explanation made by the client.

Andersen (1992:321) emphasizes that this approach does not mean that 'anything goes,' that 'I do not know anything' (Freedman & Combs 1996:44) or that the therapist's experiences and knowledge are useless. Rather, it means that the therapist is able to consider his/her knowledge no more valid than those of the client. According to Andersen (1993:321), the client has local experiences, while the therapist has general experiences. Both must then be applied to the deconstruction process.

Anderson and Goolishian (1992:29) regard the therapeutic conversation as an 'in there together' process, where people talk 'with' one another and not 'to' one another. This means that a therapeutic conversation becomes a collaborative effort of generating new meaning based on the linguistic and explanatory history of the person, and that his or her story is continually retold and elaborated through the therapeutic dialogue.

'Externalising' is an approach to therapy that encourages persons to objectify and, at times, to personify the problems that they experience as oppressive. In this process, the problem becomes a separate entity and thus external to the person or relationship ascribed as the problem (White 1988/9:5; White 1992:126; White & Epston 1990:38). When a person seeks therapy, it is not unusual for her or him to present a 'problem-saturated description' (White 1988/9:5; White & Epston 1990:39) as a dominant story of her or his life. People present their problem-saturated story when they have internalised the problem – they see themselves as the problem. White (1988/9:6) introduces the idea that the person, or the relationship between persons, is not the

problem, rather the problem is the problem. In this manner, the relationship between the person and the problem becomes the problem.

White (White & Epston 1990:39,40) concludes that there is a positive response to externalising conversation, since such an approach

(1) decreases unproductive conflict between persons, including those disputes over who is responsible for the problem; (2) undermines the sense of failure that has developed for many persons in response to the continuing existence of the problem despite their attempts to resolve it; (3) paves the way for persons to cooperate with each other, to unite in a struggle against the problem, ...; (4) opens up new possibilities for persons to take action to retrieve their lives and relationships from the problem and its influence; (5) frees persons to take a lighter, more effective, and less stressed approach to 'deadly serious' problems; and (6) presents options for dialogue, rather than monologue, about the problem.

White (White & Epston 1990:39,40) refers to "relative influence questions" which assist people to externalise a problem. A first set of questions encourages people to map the influence of the problem in their lives and relationships and a second set encourages people to map their own influence in the 'life' of the problem. By using externalising conversation, a person has an opportunity to take control over her or his own life and take responsibility for solving the problem. Externalising conversation empowers a person to stand up against the problem. Externalising conversation also gives a person space to explore her or his alternative stories and preferred realities of who she/he might be.

Wylie (1994:43) quotes White, who argues that "there is always a history of struggle and protest, always." White and Epston (1990:55) look for evidence of what they call the *unique outcomes* or *alternative stories* in people's lives and the *counterplots*. For an event to become a unique outcome, it must be qualified as such by the person to whose life the event relates. Unique outcomes provide a gateway to what we might consider to be the alternative

territories of a person's life (White 1992:127). When it is established that particular events qualify as unique outcomes in that they are judged to be both significant and preferred, the therapist can facilitate the generation of and/or resurrection of alternative stories by orienting herself/himself to these unique outcomes as one might orient oneself to mysteries.

White (1992:127) maintains that a therapist can facilitate this process, which he calls 're-authoring,' by asking a variety of questions. He includes 'landscape of action' and 'landscape of identity or meaning' questions (White 1992:127). These terms are described by White (1992:127) as follows:

Landscape of action questions encourage persons to situate unique outcomes in sequences of events that unfold across time according to particular plots. Landscape of consciousness [identity or meaning] questions encourage persons to reflect on and to determine the meaning of those developments that occur in the landscape of action.

These unique outcomes and alternative stories have to be internalised, because they are the success stories of a person's life.

A narrative approach emphasises transparency, reflexive conversations and accountability. White (1992:144) uses Epston's notion of transparency to describe the deconstruction of the therapeutic process. Multiple reflexive conversations used in post-modern discourse act as ways of deconstructing the power/knowledge relation (Kvale 1992; Steier 1991). In this way, the number of interpretations are expanded and 'subjects' are made 'participants', co-producing research, training and therapy (Kotzé & Kotzé 1997:37). Through transparency, the therapy is deconstructed, in such a way that the participants can reflect on the process of communication. This process contributes to a context in which people are more able to decide for themselves how they might take the therapist's responses (White 1992:144). Thus transparency involves a deconstruction of the power of the therapist, declaring the therapist or researcher equal to the clients or participants.

Accountability is most significantly about addressing power differences. McLean (White 1995b) interviews White about the implications of accountability for therapy. White (1995b:166) argues that there is a power differential in the therapy context, and that it is one that cannot be erased, regardless of how committed we are to egalitarian practices. White (1995b:168) maintains, however, that despite this:

I have an ethical commitment to bring forth the extent to which the process of therapy is a two-way process, and to try to find ways of identifying, acknowledging, and articulating the extent to which the therapeutic interactions are actually shaping of the work itself, and also shaping of my life more generally in positive ways.

Accountability requires therapists and researchers to confront the ethical responsibilities involved in the work they are doing with regard to the people they are working with.

2.4 METHODOLOGICAL PROCESS

The methodological process used in this research project is based on the article of Müller et al (2001:76-96). These theologians used Anne Lamott's model for fiction writing as a metaphor for doing research from a narrative approach. The writing metaphor emphasises the wholeness of the research process.

Müller et al (2001:79ev.) propose that the story be developed by using the 'ABDCE formula' as methodological point of departure. This formula can be outlined as follows.

Action: These are stories of actions (doing things) that are told. The stories include the problem, but primarily deal with the "now" of the stories. In this process the researcher takes the point of "not knowing" (Müller et al 2001:79-81). Questions which may be asked are: Which action or action fields are being investigated? Why the particular field? What is the relationship with the different role-players? How do you form part of the action?

Background: Background refers to the preceding events to the story. The people involved in the story have a specific religious and cultural background (Müller et al 2001:82-83). The “now” of the story is placed against the current socio-political and economical background. Relevant questions are: Who are the persons playing a role in the development of the story? What must be researched in greater depth? Which stories form the background to the current story?

Development: The “plot” or story line of the drama develops over the course of time. The development takes place in interaction with the “co-researchers”. They form part of the development of the story (Müller et al 2001:84-86). Morgan (2000:6) describes the development of the story as follows: “as more and more events are selected and gathered into the dominant plot, the story gains richness and thickness.” Questions that may be asked are: How do the different stories “join in dialogue with each other”? Which unexpected twists are there in the development of the stories?

Climax: Understanding should not come too soon, but should grow in time. The climax cannot be simulated, but should be waited for patiently (Müller et al 2001:89-90). The question is: What is the climax of the story? How do the “co-researchers” see the climax?

Ending: The ending of the story is not closed off but open, the story continues. The end is probably the introduction to a subsequent story (Müller et al 2001:89-90). The question that should be answered is what the end of the story is.

This is no linear process, but rather reflects an emergent design which is focused, but nevertheless flexible, iterative and continuous and therefore gives this research the character of an evolving spiral.

2.5 RESEARCH EXPERIENCE

2.5.1 Ready, Steady, Research!

I designed a blueprint of how I intended to conduct my research. I would borrow methods of data gathering from my quantitative research neighbours. I would conduct my research through semi-structured conversational interviews with a focus group representative of the women infected and/or affected by HIV/AIDS, according to my criteria (outlined below).

I would tape record the semi-structured conversations with the focus group, write it down and present it to the focus group at each following session for them to make additions or admissions and clarify certain issues, ensuring respondent validity (Silverman 2001: 233). I would not transcribe the recorded interviews since I be using a translator. Her translations would to some extent be interpretations of the stories and the purpose of transcription would already be defeated.

I would sample a group of six to eight women in Atteridgeville. Why Atteridgeville? In 2001, the Department of Social Development in the Tswane region in the Gauteng province approached Heartbeat to initiate an orphan care project in Atteridgeville. The Department had been funding another Heartbeat project in the Merafong municipal area (Gauteng province) since 2000. At the time of this request, there were no existing government funded non-governmental organisations in Atteridgeville which provided care for the many children orphaned, mainly as a result of HIV/AIDS.

Heartbeat subsequently received funding from the Department of Social Development and engaged in Atteridgeville in April 2002. My roll as General Manager of Heartbeat in the engagement process with a new community is to introduce the aims and objectives of the organisation to relevant stakeholders in the community, to choose an appropriate partner organisation for our intervention, to establish a rapport with the stakeholders and the partner organisation, and to appoint project staff.

By the time I introduced my research project in Atteridgeville (January 2003), Heartbeat was well-known to the community and I had established a good rapport with the community leaders and other stakeholders. Heartbeat partnered with the Atteridgeville Presbyterian Church for our intervention and I had established a solid relationship with the church leaders who had also invited me to do a sermon on HIV/AIDS. I had appointed both a community leader, as Community Development Facilitator, as well as an orphan care Team Leader. Both of the new Heartbeat employees were members of the Atteridgeville community and the Atteridgeville Presbyterian Church.

Early in January 2003, I met with the Community Development Facilitator and the orphan care Team Leader of Heartbeat to explain the aims and objectives of my research project to them. I gave them each a copy of the information letter (Appendix A) and asked for their input on the viability of such a project in Atteridgeville. Not only were they community members of Atteridgeville, they were also working with children orphaned by HIV/AIDS and children staying with terminal ill parents. They were both excited at the prospects of the project. The childcare Team Leader said that people would participate “because there seems to be someone who cares”.

The sample of women would be chosen bearing in mind the criteria developed by Morgan (1997). “[P]urposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample case carefully on this basis” (Silverman, 2001:251). Accordingly, the women that would be sampled had to fit the following criteria:

- 1.) they had to be either living with HIV/AIDS, or
- 2.) caring for a relative(s) living with HIV/AIDS or,
- 3.) both living with HIV/AIDS as well as caring for a relative(s) living with HIV/AIDS.

I was more interested in listening to the stories of care at household level than the stories of care at community level. I wanted primarily to listen to the

stories of care of people infected and their relatives subsequently affected (by ways of caring for the infected person). These relatives could even be infected themselves while caring for an infected relative.

These criteria are derived from my construction of what constitutes women infected and/or affected by HIV/AIDS. My sampling was purposive and directed at certain inclusive criteria (Bobbie and Mouton 2001:288). Morgan warns against only one focus group as it can severely hamper the results of a study, since the researcher may, for instance, not be able to tell what impact the group's dynamics had on the data, and so on. However, my experience working in the HIV/AIDS field informed my decision to only make use of one focus group, as I was aware of the stigma attached to people living with HIV/AIDS and their subsequent reluctance to come forward to reveal their status. The people of Atteridgeville have also been the research objects of multiple projects on HIV/AIDS because of the presence of an academic hospital, Kalafong, in the area. Their experiences of previous research projects may influence or colour both their willingness to participate in yet another research project as well as the nature of their participation. I assumed that it would therefore be difficult to identify more than six to eight people to participate in this project.

I subsequently planned to gather a reflective group to reflect on the stories of the focus group and to bring their own stories of care into conversation with those of the focus group. This group would be constituted of carers in the community, working as volunteers or paid staff with community home-based care groups in caring for people living with a terminal illness. Community home-based care is defined by Van Dyk (2001:327) as

the care given to individuals in their homes when they are supported by their families, their extended families or those of their choice. These home-based caregivers are supported by a multidisciplinary team and complementary caregivers who are able to meet the specific needs of the individual and the family.

According to Fröhlich (1999:4) the team consists of all the people who are involved in care and support and may include medical practitioners, nursing supervisors, social workers, health educators, physiotherapists, occupational therapists, AIDS health promotion workers, volunteers, traditional healers, and/or religious healers.

I would call both groups together (the focus group and the reflective group separately) at an information session, where I would share the aims and objectives of the research project. I would allow ample time for questions and answers to clarify terminology, methodology and ethical issues. I would explain to the groups that their participation was voluntary and try all means possible to ensure that they made informed decisions about giving their consent, since I realise that voluntary participation is “ ... far easier to accept in theory than it is to apply in practice” (Babbie & Mouton 2001:521). I would ensure that all members of the focus group sign informed consent sheets as people with HIV/AIDS have the right to confidentiality and privacy about their health and HIV status (Van Dyk 2001:408).

I would then conduct twenty group sessions with the focus group of infected and/or affected women through (semi-structured) conversational interviewing (Pare 1995:1). The interviewing would take place at the Presbyterian church in Atteridgeville from where Heartbeat operates. I would also make use of a variety of deconstructive and reconstructive questions developed for narrative research., These include opening space, preference, meaning, story development and story construction questions (Freedman and Combs 1996:124-143). I would engage in the technique of *simple observation*, where the researcher remains an outside observer (Babbie & Mouton 2001:293). I would observe and document exterior physical signs, expressive movements, physical location, language behaviour and time duration (Denzin in Keller 1993).

A translator would be recruited and informed about the research project as well. She would also have time for questions and answers before signing an informed consent sheet herself. The purpose thereof would be to ensure that

she kept all information confidential and that she committed herself to participation in the project to its end. I would explain to her that she had to translate the words of the women as close as possible to their own words (without the use of metaphors).

I would conduct five group sessions with the reflective group, one after every four sessions with the focus group. I would not tape-record these sessions, but take notes during discussions. These notes would be brought into conversation with the recorded interviews and visa versa.

My research gun was loaded with arsenal, and I was ready to shoot ... and kill?

2.5.2 Not so fast!

Van Deventer (2002:9) remarks that “research is not in the first instance about an action, but about people (characters) in action. These characters are participants and not objects. They are the co-researchers and should be allowed to be part of the evolving process.” As co-researchers, then, they will play an intrinsic role in how the research project progresses and evolves since they will in a large part determine the direction of the project. Co-researchers (Argyris and Schön 1991; Chesler 1991; Dugan 1993; Elden and Chisholm 1993) should thus participate through all the phases of the research. “Participation implies that members of the subject of study are integrated in the research by participating fully and actively in the research process, from its outset and throughout most, or all of its phases” (Babbie and Mouton 2001:315). Participatory or collaborative research

... is designed to create social and individual change by altering the role relations of people involved in the project. This model can be limited to a slight modification of roles or expanded so that all participants have the combined researcher/subject role. In feminist participatory research, the distinction between the researcher(s) and those on whom the research is done

disappears. To achieve an egalitarian relation, the researcher abandons control and adopts an approach of openness, reciprocity, mutual disclosure, and shared risk. Differences in social status and background give way as shared decision-making and self-disclosure develop.

Participatory action research (PAR) is of special relevance to researchers working in South Africa, not only because, as Babbie and Mouton (2001:314) note, there are a, “large number of South Africans living in ‘Third-World’ conditions,” but also because of its “bottom-up” nature, deconstructing development projects implemented in a technocratic manner from above during the apartheid regime, and because patriarchal discourses which render women voiceless and powerless are deconstructed by such an approach.

Yet it cannot be assumed that women are automatically on equal footing with other women or that women from different classes and/cultures will accept the other as their equal. Reinharz (1992:65) notes that feminists’ access to women is problematic especially when there are differences of social class, race, ethnicity, or sexual preference. These differences are themselves imbued with power and women are likely to adhere to the assumed power relationship. I found that in the South African context where individual’s identities were politically constructed for many years, to achieve participation in cross-cultural research the establishment of relational partnerships with potential co-researchers was a crucial element of engagement in the research process. I am a white, middle class, educated woman aiming to do research with black, poor, and mostly uneducated women infected and/or affected by HIV/AIDS (a highly politicised and stigmatised disease in South Africa). I am associated with the atrocities of white minority rule and, as a consequence, I was distrusted from the day I set foot in the township. This distrust can be deconstructed through the establishment of relational partnerships. A bond of sisterhood must be earned so to speak.

To earn this bond, it was necessary to pause and reflect on the ethical implications of my research agenda from the outset. It was true that I identified the research problem, the research questions and the research aims

in collaboration with the SANPAD team. I had also designed a blueprint of how I intended to conduct my research. It was at the point that I had to admit that I was well on the way to determining the outcomes of the entire research process without any participation from my co-researchers. I had to honestly admit that I was a product of the positivistic school and that I would have to critically reflect on every step of the process to ensure that I moved within the post-modern paradigm I believed in and not the positivistic paradigm within which I was born and bred. Fortunately, my relational experience with the community and the potential co-researchers, (elaborated later in this chapter) early in the implementation phase of the project deconstructed this power discourse of control.

2.5.3 The Translator/Co-researcher

I asked the Orphan Care Team Leader if she would be willing to assist me with the translation of the stories as I wanted to listen to the stories of these women in their own language. I was afraid of constraining their story telling, should I insist on English narrating. Also, I assumed that many of these women might not be able to speak English at all.

I deliberately approached the Orphan Care Team Leader, rather than the Community Development Facilitator, to act as translator. The Team Leader was very young (22 years old) and had no political standing in the community. The Community Development Facilitator, however, was well known as an ANC activist and also an older woman (“gogo”). I judged that her political background and her age may potentially influence the story told to her by my other co-researchers as well as the story she related to me. The Team Leader, on the other hand, was of similar age to my primary co-researchers (therefore establishing a measure of equality between the women) and of no obvious political standing which might influence the how the family responded to her presence. I therefore asked the Team Leader to act as my translator. I explained to her what was expected and she subsequently signed an informed consent sheet (Appendix 5).

By making this choice I attempted to challenge the possibility of the African cultural power discourse of respect for elders standing in the way of listening to the stories of women from all ages. In African culture you deserve respect by virtue of your age. This respect includes not looking your elders in the eye when talking to them, curtsying when greeting them and respecting (which implies obeying) their opinion. Decision-making in the community depends on the wisdom of the elders. I was concerned that should I co-opt an older woman as translator, the younger women in my research project would not share their multiple stories in fear of being disrespectful to their elders. I also wanted to ensure that my research is not affiliated with the agenda of any political organisation, as the South African media often refers to HIV/AIDS as a politicised issue. I hoped that my deconstruction of the power structures amongst my co-researchers would allow the project to operate within these structures whilst simultaneously limiting their negative impact on the research outcomes. While it would be impossible to completely erase the power structures I could shape my project in such a way that there was equality amongst the co-researchers.

2.5.4 The Participants/Co-researchers

I selected my sample on the basis of the nature of my research aims and based on my judgement and the purpose of the study (Babbie & Mouton 2001:166). The aim was not to select a sample which would be representative but rather “to collect specific cases, events, or actions that can clarify and deepen understanding” (Neuman 2000:196).

I asked the Orphan Care Team Leader, Mpeki, to assist me with this purposive sampling as she knew the community members better than I did. I discussed the criteria for the purposive sampling with her. I again provided her with information sheets as well as informed consent sheets with which to approach possible co-researchers. As these sheets were in English, I asked her to translate the content to the women whom she approached. I also asked

her to invite these women to an information session at the Church on a particular date so as to explain the research project again, allow for a question and answering session and put together a focus group of women infected and/or affected by HIV/AIDS according to the set criteria. This focus group would then constitute my co-researchers.

Mpeki phoned me four days later, explaining that she wanted my advice. Apparently, the husbands of some of the women who she had approached, were also interested in the research project. I explained to her again that the project was only for women who fitted the set criteria. Although she understood the criteria perfectly, she had an ethical dilemma: she did not know how to explain to these men that they were not welcome because of their gender. It could be interpreted that we did not want to offer them any support. There was also nowhere to refer them to, as there were, according to these men, no support groups in Atteridgeville who would cater for men living with HIV/AIDS. She experienced another difficulty since the women living with HIV/AIDS that she had identified were too weak to walk to the church. I would have to visit them at their respective homes. It was at this moment in time that I started lowering my gun.

I shared the difficulty of the men with *Heartbeat's* Program Manager in Tswane and the East Rand, who agreed to meet with the men to see how she could assist their specific needs. I subsequently agreed to meet with the women and their husbands, together with the Program Manager who would then facilitate the discussions of the men at the meeting.

I was extremely disappointed when only one elderly woman, living with HIV/AIDS, attended the meeting. Her husband as well as another man, living with HIV/AIDS, also attended. I could not chase the husband out, as this would imply some clandestine activity on my side. Instead I proceeded to explain the research project to the group again. Mpeki translated the conversation. I asked the woman how she would like me to address her. She wanted me to call her Mamma C. From then on, I addressed her as such. She agreed that she understood the project and would like to participate. However,

I needed to provide her with transport money, if I wanted her to meet me at the Church for the interviews. She stayed in the informal settlement in Atteridgeville and she had to travel with a taxi to the Church. I enquired as to whether she would mind if I visited her at home. She agreed to this arrangement. She signed the consent form and I gave her five rand for taxi fees.

After the meeting, I walked with Mpeki to the home of another potential co-researcher. She stayed approximately 100 metres from the Church. I remember this experience vividly. I was neither prepared for what I was to encounter, nor did this encounter fit into my well-thought through plan of the research process. On the way to the potential co-researcher's home, I enquired from Mpeki how she knew the lady that we were about to visit. Apparently it was a friend of a friend. Mpeki explained that she was very young. Some men, sitting on the sidewalk, stared at us walking past. Loud music filled the air. I felt extremely uncomfortable as their eyes pierced my back. We entered through a dilapidated gate and walked along the side of the matchbox house to a back room separate from the house. Two beds, connected by a bed table, took up most of the space in the room. They were neatly covered with bright green and blue duvet covers and cushions. I noticed some drawers in one corner. A man in uniform smiled at me from the wall. It was only then that I noticed the opening in the wall next to the one bed.

I could see the foot end of a big bed through the opening. Mpeki stepped through the opening in the wall. I heard her softly calling a name. She called again and indicated to me that I could come in. I was not at all prepared for this encounter. A terrible stench nearly drove me out of the room again. I saw the tiny frame of a body curled up in the middle of the double bed. A towel barely covered her legs and her body. The mattress was bare, except for the towel and the diaper on which she laid. I noticed some washing in a plastic basket in one corner. Next to her bed was a small plastic chair with a bucket. Inside the bucket were two mangos. Mpeki showed me where to sit. She went to fetch another chair from the pretty room. The body had huge eyes, sunken into her skull. As she tried to make herself comfortable, Mpeki picked up the

towel to cover her legs. She was naked from the middle down and her legs were covered with sores. I looked away, partly because of shame on her behalf, partly because I was repulsed by what I saw. The rest of her body was covered with a rash which she constantly scratched while we were talking.

Mpeki introduced me to Dina and visa versa. I had a desperate urge to finish this conversation as soon as possible so that I could leave this uncomfortable space. I started talking about my research project with little enthusiasm. Dina asked me to slow down as I was talking too fast. I talked slower and Mpeki translated to make sure that Dina understood.

Dina immediately started talking about how loneliness and fright got a hold of her life, before even signing the informed consent sheet. I interrupted her, explaining that we must first sign the informed consent form. I had the tape recorder with me and decided there that I should tape the conversation. I showed her the tape recorder and asked her permission to tape our conversation. I explained to her that her story was so important to me that I didn't want to miss a thing.

As she took the pen to sign the consent sheet, I noticed that her hand was firm and not shaky as I expected. I also explained that this was an introductory session and that I would visit again the following Friday. I asked her if I could bring her anything she'd like on my next visit. Despite the urge to leave, I also felt desperate for some act of mercy for this skeleton. She asked for yogurt and chocolate. As I waved her goodbye, she was still scratching.

I walked back to the Church in silence, pondering on my experience. I was in search of words to come to terms with the terrible suffering that I had just witnessed. I felt terribly confused. I had an urge to get Dina some medicine to stop the scratching, the pain, the humiliation and the suffering. Images of a friend of mine, living with HIV/AIDS for more than 17 years, flashed through my mind. He was mostly in good health, because he could afford the extremely expensive antiretroviral drugs from private doctors. Unfortunately, D had neither access to these drugs at the state hospital, nor could she afford

them. I wondered how justice figured in this story. I remember also that anger, frustration, humiliation and disillusionment clawed at my heart. I was late for a meeting, but somehow that wasn't so much of a problem anymore.

I rushed home and wrote my experience down in a notebook. I included the conversation, my feelings, descriptions of the walk and the house, the interaction with the environment, really the holistic experience, in my writing. This was the first entry into what became my research diary (see 2.5.6).

A few days later, Mpeki and I went to visit Mamma C. After being chased by two stray dogs and driving around in the informal settlement for more than two hours, we gave up on ever finding her home. The street numbers were very confusing with more than one street seemingly having the same name. When we arrived back at the Church, her husband was there, engaged in discussions with the Community Development Facilitator. We asked him to meet with us at the Church the following week to take us to his home.

Despite the fact that we had agreed to meet at the primary school close to his house, he was not there. We again turned around and I decided not to include Mamma C in the project as it seemed impossible to get hold of her and the constant search was time consuming. It seemed that her husband and perhaps she might have had false expectations of the project and when these expectations were not met, they lost interest.

I consequently decided to engage in conversational interviews with Dina about care since she fitted the sampling criteria and was always available. It meant however, that I would have to visit her at her home as she would not be able to come to the Church from where I originally planned to conduct the focus groups.

The use of semi-structured interviews have become the principal means by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives. Reinharz (1992:19)

accentuates the importance of interviewing as a tool to listen to women's stories in their own words:

For one thing, interviewing offers researchers access to people's ideas, thoughts, and memories in their own words rather than in the words of the researcher. This asset is particularly important for the study of women because in this way learning from women is an antidote to centuries of ignoring women's ideas altogether or having men speak for women.

What followed after initially having only semi-structured conversational interviews with Dina, was the development of a relationship between Dina and myself and Mpeki, where I was no longer only listening to Dina's stories about care, but where both myself and Mpeki became part of her story of care and/or the lack of care. I walked along the dusty roads of Atteridgeville every time I had to visit her. People started to greet me in the street. An elderly woman reprimanded me for carrying my cell phone in my hand and told me to put it away as people might grab it. I was there when Dina's mother came to wash her. I was there when Dina's sister cried because the care burden became too heavy. I visited the municipal offices with Dina's mother and the grant offices with Dina and her sister. I experienced pain, frustration, and humiliation. I cried with the family and I laughed with them. They asked my advice on some occasions and I asked theirs on others. I was not just a passive character. True to the social-constructionist approach, I was involved with the co-researcher and the other characters in an active process of story development. My research was an experience in itself in which I was participating and learning from Dina and her family about caring and/or lack thereof.

I had engaged in contemporary ethnography or fieldwork which was included multi-method research (Reinharz 1992:46). In my case, it included observation, participation, and conversational interviewing. Reinharz (1992:46) argues that non-positivist methods – particularly open-ended interviewing and ethnography – must have a prominent place in feminist social science, because these methods focus on interpretation, rely on the

researcher's immersion in social settings, and aim for inter-subjective understanding between researchers and the person(s) studied. This is in opposition to positivist methods. The 'distance' sought by positivist methods also ensured that knowledge was skewed in an androcentric or male-orientated way. Ethnography assisted me in listening to the stories of Dina as shaped by the social context in which she lives.

The challenge for feminist ethnographers is to use the potential of fieldwork to get closer to women's realities. "Ethnography is an important feminist method if it makes women's *lives* visible, just as interviewing is an important feminist method if it makes women's *voices* audible." (Reinharz 1992:48). It is not ethnography per se, therefore, that renders this method feminist, but ethnography in the hands of feminists.

Multi-method research is time consuming, however, and I soon realised that time and financial constraints would limit my ability to include more co-researchers in my research project. "The production of participant observation studies are generally limited because of the difficulty to gain access to the study site, its time consuming nature, the inadequacy of training, the difficulty of obtaining funding and the derogatory attitude of some powerful groups within social science toward nonquantitative research" (Reinharz 1992:73). To do intensive ethnography frequently requires the ability to suspend personal and work obligations, to travel, and to expose oneself to risk.

Everyday, after my visit to Dina and her family, I would return home and write my experiences down in my research diary. I would listen to the taped conversations to add things I may have left out. I would read the written conversations to Dina at the beginning of each visit so that she could make additions or corrections on my interpretations, thus ensuring respondent validity (Silverman 2001:233). I did not however include all my observations in the readings to Dina, as many of them served the purpose of assisting me to reflect on my own feelings and fears. How could I possibly share with Dina that there was a time that I, together with her sister, wished that she would

rather die? My research diary consisted of a combination of conversations, observations and reflections, in short, my entire research experience.

I participated as a character in the care story of Dina, her mother and her sister. The outcomes of my research were being determined by these women's stories of which I was only one of the characters. Through my presence, I also met other characters in the women's stories about care and/or the lack of care: Dina's sister's two year old daughter, her uncle and his girlfriend, members of a home-based care program, church members, friends and Dina's father.

In the development of this caring relationship with Dina and her family, questions in a more formal interview situation became forced. Our interaction became purely conversational. As soon as I engaged in too many questions, I sensed a broadening distance between us and I returned to a conversational mode again. And although the tape recorder was always switched on during my conversations and interactions with Dina at her home, I could not necessarily keep it switched on while taking her to the grant offices for instance.

I did not engage in any formal interviews with Dina's family, relatives, friends or other visitors while being a character in her story (until her death). I interacted with them all as characters in Dina's story. I became a member of the family through this process. I once had to cancel a visit and Dina told me that she missed me when I visited her again. And while my eighth visit to Dina, on the 24th of March, was meant to be my last I did not plan for it to be my last visit at all.

Dina passed away abruptly on Friday, the 4th of April 2003 in a hospice. I visited her family (mother, father and sister) on the 9th of April to convey my condolences. A hospice story about lack of care evolved during a conversation with her father. I offered to pay for the toilets for the funeral and to organise some vegetables as it is customary that family members make a contribution towards the funeral. The Orphan Care Team Leader, my

translator, organised food parcels for Dina's mother and two children. Dina's mother and her children and grandchildren were included in *Heartbeat's* intervention as *Heartbeat* caters for grandmothers caring for orphans. I also referred the case to one of Heartbeat's social workers to place Dina's children in foster care (D had two daughters) with Dina's mother as this was both the wish of D and her mother.

This was not the end of my research journey. I had built strong relationships with Dina's mother and her sister through my presence. They both cared for Dina until she died. More or less six weeks after Dina's death, I met with Dina's sister Noluthando. I recorded her story about care and/or the lack of care during a semi-structured conversational interview of more than two hours. Two weeks later, I met with Dina's mother. This conversational interview was also taped.

Steiner Kvale's metaphor of the interviewer as a traveller guided the process. According to Kvale (1996:3-5), the interviewer

wanders through the landscape and enters into conversations with the people encountered. The traveller explores the many domains of the country, as unknown territory or with maps, roaming freely around the territory ... The interviewer wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world.

My semi-structured interviews with Dina and her family constituted my own journey alongside Dina in order to hear her stories. Through these interviews my journey intersected that of Dina and her family's and I was able to become a participant/actor in their stories rather than a distant outsider. My position (particularly in terms of power) was thus radically changed through active participation.

2.5.5 The Reflective Group

Heartbeat works closely with the home-based care programs in the communities where we mobilise community members to take care of orphans. The staff of the home-based care programs are often the first people to identify potential orphans as they care for their parent's until they die. These children are then referred to *Heartbeat* for intervention. I asked my translator to set up a meeting for me with a two of the home-based care programs with whom *Heartbeat* works. I met with the nursing sister of *Kaponoke Maatla* and explained the research project to her. She agreed that she had no problems with her staff joining the reflective group. As *Lapalathuso* had no formal leader, we invited the group together with the care workers of *Kaponoke Maatla* to the first reflective group session. *Lapalathuso* also agreed to participate.

The reflective group consequently consisted of an average of eight members from two home-based care programs in Atteridgeville, *Kaponoke Maatla* and *Lapalathuso*. Three childcare workers from *Heartbeat* also joined the reflective group. In caring for potential orphans, these workers were involved in the care of the whole family. The home-based caregivers were caring for people in their old age and terminally ill people. *Lapalathuso* consisted only of a group of volunteers. *Kaponoke Maatla* was supervised by a nursing sister and the volunteers in this program received monetary incentives from the Department of Health. Only three of the participants were men.

Kapanoke Maatla is engaged in activities such as home visitation, washing, feeding and counselling for terminally ill people. *Lapalathuso* assists the old aged and terminally ill with home visits to ensure that 'their patients' take their medication regularly. During these home visits they bathe, wash and feed their patients. They also provide spiritual care for the patients: "You pray for them at the end of your visit."

The research procedures I followed had to mirror the epistemology I had chosen. Accountability and transparency played an important role in the research project. Reinharz (1992:74) quotes Women's Studies scholar Renate Klein who maintains that "doing feminist research explicitly demands

transparency in all stages of our research, making visible why we do what we do – and how we do this”. Post-modern therapy approaches (for example, the narrative approach) emphasize a more equalitarian and open relationship between therapist and client, researcher and participants, supervisor and supervisee, and in this way deconstruct the power within these relationships (Kotzé & Kotzé 1997:37; White & Epston 1990). James Griffith and Melissa Elliot (1994:166) note that the “ ... use of the reflecting position ... is in essence a political act whose function is to distribute power among all the different voices in the discourse, dominant and nondominant.” Thus the premise of post-modern feminist research must be essentially political – to empower the research subject (now the co-researcher) to speak her own story and in so doing, disempower the discourses which have traditionally silenced her. Transparency and accountability allow the research subject to become a co-researcher, establishing equality between the participants and paving the way for the co-researcher’s voice to be heard.

At the beginning of each reflective session, the reflective group was provided with a verbal summary of the previous session, read from my manuscript. I could not hand everyone a copy as many of the participants were illiterate. I asked the group to listen to the summary and to make any comments, corrections or additions which they did. For confidentiality’s sake, I never mentioned my research participant’s name and the group agreed unanimously that they would only share stories they felt comfortable sharing and that they would keep these stories confidential. They didn’t sign any informed consent sheets.

I met with this group four times, reflecting on stories identified during the research process with D and her family. Their contributions provided me with useful insights into patriarchal, gender, cultural and religious discourses in Atteridgeville. They interpreted some stories gained from my interaction with Dina and her family and introduced new stories to the process.

Unfortunately, it was very difficult to manage to gather the same group of people every time. Although there were always familiar faces, new faces

appeared up to the last session. This complicated the flow of stories and necessitated the continuous negotiation of consent and confidentiality issues. Although most of these newcomers were invited by friends who had attended the previous sessions, much time was wasted introducing the research story again. Each reflective session lasted between forty five minutes and two hours.

2.5.6 My Research Diary

As the “I” was very prominent in my first encounter, I realised that I would have to be deconstructively self-critical of my own knowledge, attempting to discover new knowledge through a participatory mode of consciousness. My research diary proved to be a helpful tool in this process. Babbie and Mouton (2001:301) argue that a diary can “... represent[ing] the immediate recording of experiences, unimpaired by the reconstructions and distortions of memory”. My diary was also a tool to reflect on my research experience. “It is through the experience of reflecting on our experience that we make meaning of it” (Freedman & Combs 1996:169). Thus my meanings for the story in which I was participating were constantly created through the act of both recording in words and re-reading my interpretations of the events.

My research diary contained one hundred and sixty typed pages recording my research experience/journey. I highlighted recurring themes and discourses, not to be examined rigorously but to bring into conversation with the documented stories gathered during my conversations, as well as literature stories, government papers and strategies about women, HIV/AIDS and care.

2.5.7 A Letter to Mpeki

Mpeki’s ‘assigned’ role, by myself originally, was that of translator. However, in the process she also became a friend of the family and her caring not only became a part of the reconstruction of Noluthando’s story, but she also

authored her own preferred story through her caring experience. The research experience had a profound influence on Mpeki's life. As a result of this development, I also engaged with Mpeki as a 'co-researcher'. Not only did I reflect on our research experience with the family with her, I also reflected on her own development. This culminated in a letter to Mpeki.

David Nylund (1994) did a survey of 40 people who had worked with him in research projects. His results showed that the average letter was worth 3.2 interviews. Freedman & Combs (1996:208) write about the meaning of letters in co-authoring stories in therapy :

Letters not only thicken the story and help the people we work with stay immersed in it, but also involve us more thoroughly in the co-authoring process, giving us an opportunity to think about the language and the questions that we use.

My letter to Mpeki assisted me in understanding the outcome of Mpeki's story.

2.5.8 Literature Stories

During my research experience, I read relevant literature on socio-cultural constructs of care. I read biographies and autobiographies on the history of South Africa and its impact on the stories of women. I studied academic and popular literature on HIV/AIDS and care in the context of HIV/AIDS. I also read stories on the experiences of black women in the world – stories of discrimination, sexism, patriarchy, and the influence of cultural and religious customs and norms on their lives.

Browning (1991:61) uses the term "thick description" to emphasize the necessity to interpret the action that is being researched against the backdrop of different perspectives: sociology, psychology, economy etc. After this thick description, and as part of it, the background should be extended to the historical perspective and the systematic concepts already developed,

concerning specific, or related actions. During this phase of the research process the “now” of the story is set against the current socio-political and economic background in which the researchers and co-researchers are busy writing their own life stories. My reading of literature stories assisted in my efforts to place the story in which I was participating and researching in context. The process allowed me to analyse the stories not as if they were in a vacuum but as if they were a product of and a reaction to the discourses (the times) in which they were produced.

2.6 CRITICAL REFLECTIONS ON ETHICAL CHOICES AND CONSIDERATIONS DURING THE RESEARCH EXPERIENCE

When I started my research, I honestly couldn't claim that I was acting only, or even primarily, in my co-researchers' interests. I wanted to do this research mainly in order to 1) obtain credibility for myself and my organisation within the HIV/AIDS care field; and to 2) obtain a doctorate degree. My own self-interest rather than the client's best interest controlled the initial care towards the research participant. I identified the research problem and I determined the research questions and aims.

However, my relationship with Dina deepened with every encounter. As soon as I became a character in her story of care, she started creating new meaning for herself from painful and abusive stories while I was merely present. Rodriguez maintains that “... our redemption ultimately resides in our openness and compassion rather than in the Truth of any one interpretation or meaning” (2002:4). My willingness to let Dina's voice speak in my research and to let the stories she wrote and re-wrote in my presence direct my project ultimately overcame the self-interest on my part which had guided the project in its initial stages. Lamott emphasises the importance of respect in the research process. She argues that “[i]f you look at people and just see sloppy clothes or rich clothes, you're going to get them wrong”

(1995:99). Writing (and research) always includes a moral responsibility. According to Lamott (1995:107) you have to care to be a great writer:

To be a good writer, you not only have to write a great deal but you have to care. You do not have to have a complicated moral philosophy. But a writer always tries, I think, to be part of the solution, to understand a little more about life and to pass this on.

The act of caring, of investing yourself in the relationships, leads to greater understanding. Your investment also leads to trust and respect, a result which was illustrated dramatically for me as my relationship Dina and her family deepened. I had become a part of their lives and their family.

Dina became a co-researcher in the true sense of the word. She determined the development of her story and the outcomes of the questions and aims. I was a traveller on a journey into the unknown. My only guides were the ethical principles embedded in my paradigm and my choice of methodology. Transparency, frequent reflection and accountability became paramount ethical principles on my journey. I realised that what had begun as a selfish endeavour with a stranger, ended as a journey with a friend. An alternative research story had developed.

This realisation led me to reflect on my earlier impetus to begin the research. Why did I want to listen to the story of Dina? Was it a matter of entertainment, a case of “voices of difference likely to bring us what we can’t have and to divert us from the monotony of sameness?” (Trinh 1989a:88) I am asking a black woman to share her story with me, a white researcher with a curious interest, it might seem, in black terminally ill women. And I am claiming the privilege of the writing up of this story. Is it possible, as Spivak asks, that “ ... alliances might then be possible between white, heterosexual, able-bodied and middle- class women and women on the margins” (1990:47) when we, as researchers, are more secure in our respective commitments to probing beneath the surface of what we know, to how we know? I assumed that because Dina was an oppressed woman, she would want to tell her unheard

story? What about her right to silence. Trinh argues that “[s]ilence as a will not to say or a will to unsay and as a language of its own has barely been explored” (1989a:373). Had I completely disregarded the possibility that Dina’s silence was an act of empowerment in itself, a way of telling her story to the world by the words she wasn’t using?

I realised that before even engaging with my co-researcher in conversation, the relational power discourses already existed by the mere fact that I was a white, middle-class, well-educated woman doing research with a black, impoverished, terminally ill woman without any tertiary education. I knew from my experience with my work in black communities during the past four years (1999 – 2003), that the expectation already existed that I would bring some resources into Dina’s family because I am a white woman. In South Africa, white people, as the beneficiaries of ‘apartheid’, are still perceived as ‘resourceful’ and black people as ‘resourceless’ even though there is a rising class of black professionals.

Reinharz (1992:123) mentions that feminists doing cross-cultural research seem to be confronting two competing sets of ethics – respect for women and respect for culture. She suggests that each person contemplating such research must decide where she stands. In listening to the stories of women being the culturally constructed caregivers in society, I struggled to respect a culture that burdens impoverished women, struggling merely to survive, with the extra load of caring for the sick. I experienced bitterness as Dina’s mother and sister struggled to carry Dina to the car, while not one of the male onlookers would lift a finger to assist us. I experienced an aching in my heart for Dina’s mother who now had to take care of seven small children with all the savings of the family being depleted by the funeral of Dina, as according to Dina’s mother, “this is how things are done in our black culture.”

Although I also realized the importance of accounting Dina’s story in her own language, I was constrained by the fact that I could not speak SeSotho. Dina had the opportunity to convey her story in her own language, but the fact that I couldn’t understand SeSotho hindered my ability to capture her story in her

own words. However, there is no understanding in the world that can escape the subjectivity and limitations of our different languages. Rodriguez (2002) argues that language is incomplete. Our narrativeness exceeds and precedes language. Meaning is found within and between words and symbols. Because we are not entirely languaged beings, language does not have the power to contain and limit us. Interpretation simply makes for new and different meanings, experiences, and understandings, and no interpretation or meaning is ever complete. While the act of interpretation creates new meanings, even should I speak SeSotho, Dina's story exceeds and precedes the language with which she speaks it. Meaning for me would still not be complete. Therefore, I argue a case that is ethically accountable to my choice of methodology, that in cross-cultural narrative research language is not necessarily a barrier to understanding and interpretation.

Another issue raised during the project was that of consent. Is informed consent really possible in cross-cultural narrative research with poorly literate people marginalized by society? Explaining the aim, methodology and notion of multiple narrative meaning to educated people in their own language already poses a challenge as they are unfamiliar with the social research jargon. I realised that my translator also didn't have a clear understanding of the aim of my research and she had to translate it into another language to a poorly educated co-researcher. I am however, not prepared to silence Dina's voice by excluding her from the project on the notion that she doesn't grasp the meaning of multiple narratives as Gottlieb and Lasser suggest (2001:32). As a feminist and contextual liberation theologian my ethical responsibility lies with creating the opportunity for the voiceless to tell their stories. As an alternative to once off informed consent, I acquired continuous consent from my co-researcher as the narrative process unfolded, as power discourses were deconstructed and as Dina shared more and more of her story.

I sensed unease with my co-researcher when I initially interviewed her through semi structured interview questions. The many questions made her anxious and seemed abusive to me. I later adopted a purely conversational style and started to participate in the daily activities of the family. It was

through this activity of participation that power was deconstructed to such an extent that Dina and her family started sharing family problems and stories of stigma and abuse as illustrated in the story of the girlfriend who turns of the main switch at night From these experiences I understood that “the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship” (Oakley 1986:41).

I became an honoured member of the family through my presence. This brought new ethical matters to the forefront. My opinion was asked on family and community matters. I gave it only when asked and assured the family time and again that this was only my opinion and not necessarily the right one. In close family matters, as is the case with the relationship between Dina and her sister, Noluthando, I took on the role of facilitating the outcome of an alternative story of care rather than directly intervening as I was concerned that this would destabilise the trust which had been built.

The discourse of the medicines posed, what I thought at first, another ethical dilemma. Dina was not using the Western medicines prescribed by the clinic, except for the *Stopitch*, was and was instead using the traditional medicine from her Church. I initially felt that this was adding to the deterioration of her health and I tried to persuade her to abandon the traditional medicines for the Western medicines that I believed would be more effective. It was only after I understood that the Western medicine, *Stopitch*, was ineffective against her itching, that an alternative story developed in my mind about the use of alternative, ‘spiritual’ medicines.

I could not hide the “I” in the circumstances where I was working. The smell of the bacterial infections affected me to such an extent that after my first encounter, I became nauseas if food smelled too strongly. When Dina wanted me to look at her bedsores, I changed the subject because I could not face it. I was repulsed by the open sores on Dina’s legs that oozed blood and pus. There was a time when depression nearly overtook the family, a time when I

prayed that Dina would rather die. I went through a phase of denial when I couldn't 'fix' Dina's condition with Western medicines. I got angry with the way she was exposed to the community and the rough manner in which she was manhandled by volunteers at the community hall. I scolded the vendor who sold black plastic bags while I was trying to cope with the difficulties that Dina faced.

Dina also asked me out about my family and I shared many stories with her about happenings in my life. She gave me advice which I followed and which had a positive outcome. A poorly educated woman (according to Western standards), who was terminally ill and whose life story was influenced by cultural discourses totally different from my own cultural background was able to advise me on my life. The discourse of the expert possessing the knowledge in my culture was challenged radically. A new alternative story on what constitutes expert knowledge formed in my mind.

I could also see my co-researcher benefiting from my presence. I reacted to Dina's definition of care. Care, according to her, was to laugh and talk with her and to give her to eat what she liked and not what other people decided on her behalf. She wanted chocolate and fruit juice and I brought her chocolate and fruit juice. She conveyed to Mpeki, my translator, that she missed me. She became upset when I skipped a visit.

Through caring for my co-researcher, I deconstructed the discourse of race and culture and I was accepted as one of the family. My friendship with Dina's family has become part of my life and is no longer only a research project. It is not only unethical but also impossible for me to break off ties with the family. I am committed to this family and this is true to a hermeneutic of deed as described by Bosch. I am indeed 'doing' theology.